

A SURVEY OF GENETIC COUNSELING PROFESSIONALS  
IN THE SOUTHEASTERN UNITED STATES: ACTUAL  
VERSUS PERCEIVED ROLES

By

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To my parents, Bentura and Christine James, my siblings,  
Berris, Audrick, and Patsy, my nieces, Isheba and Sharifah,  
for all their love and support.

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Abstract of Dissertation Presented to the Graduate School  
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A SURVEY OF GENETIC COUNSELING PROFESSIONALS IN THE  
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By

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This study was part of an Ethical, Legal, and Social Implications of the Human Genome Project (ELSI) grant funded by the Department of Energy (DOE) and the National Institutes of Health (NIH). It was conducted under the aegis of the Morehouse School of Medicine in Atlanta, Georgia, and the University of Florida College of Medicine in Gainesville, Florida. As part of the project, the current study sought to answer the following questions: 1) What are the qualifications and training of professionals in the southeastern United States who provide genetic counseling? 2) Who routinely does and who should do genetic counseling? and 3) What are the educational methods used by the different health professionals in genetic counseling? A self-administered mail survey was sent to 325 potential genetic counseling professionals in the southeastern United States (Alabama, Florida, Georgia,

Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee). Two hundred four persons volunteered for the study. Genetic associates (31%), physicians (30%), and nurses represent the three largest groups of health professionals involved in the genetic counseling process. Genetic counseling is usually a team activity. The majority of respondents reported that social workers are not and should not routinely be involved in genetic counseling. Genetic associates are well trained in human genetics and counseling techniques, but like physicians and nurses have much room for improvement in the educative aspect of counseling. Physicians have more years of experience (13 years) doing genetic counseling than genetic associates (6 years) and nurses (6 years) but the bulk of their training apparently comes from supervised clinical training rather than formal courses in human genetics, counseling techniques, and educational methods and principles. Nurses and genetic associates have comparable years of experience but nurses lack the formal courses in human genetics and counseling techniques. The majority of all respondents had no formal training in educational methods and principles. Educational techniques such as assessing clients' educational level and asking patients to repeat information in their own words were not always utilized. Recognizing professional limitations and formal training in human genetics

are the only two factors perceived to increase counseling effectiveness. Policy recommendations are given.

CHAPTER 1  
INTRODUCTION

Recent advances in medical genetics have resulted in a demand for more and better genetic counseling services. These advances have included increased knowledge about how certain diseases are inherited, the ability to detect chromosomal abnormalities, and prenatal diagnosis of certain diseases. Individuals now have more opportunities to understand their biological heritage and to make their health care plans and reproductive choices accordingly. As technology advances through spinoffs of research sponsored by the Human Genome Initiative/Human Genome Project (HGI) and other genome research, cheaper and more accurate tests for diseases will be readily available. An even greater incentive for genetic disease screening will follow the availability of adequately developed gene therapy which also is anticipated to be developed as a result of research funded through the HGI.

As the technology grows, there also is the potential for overwhelming the existing health care system. How will genetic counselors keep current in this voluminous field of information? In 1991, the National Society of Genetic Counselors estimated that there were less than 600 nationally certified genetic counselors. Because of the shortage of

nationally certified genetic counselors, other health professionals engage in the process of genetic counseling.

Genetic counseling is usually provided by four groups of people: physicians, nurses, social workers, and master's trained genetic counselors (genetic associates). Because different types of people (with varying qualifications and different levels of training) provide genetic counseling, it is necessary to explore the distinctions between providing genetic information, providing genetic education, and providing genetic counseling. Who is qualified to do what? Is there a need for role delineation? Should only master's trained genetic counselors provide genetic counseling? Are some patients (e.g. indigent and rural patients) more likely to be counseled by less trained individuals? Issues such as who genetic counselors are, what their qualifications are, how they are trained, what their roles are as members of the health care team, and what constitutes genetic counseling become complex when carefully examined.

#### Genetic Counseling

Genetic counseling is the current health service approach to educating about and possibly preventing many genetic diseases. There are numerous definitions of genetic counseling in the professional literature. Fraser's (1974) definition of "genetic counseling" is one of the most comprehensive:

. . . a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or the family to (1) comprehend the medical facts, including the diagnosis, the probable course of the discourse and the available management; (2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk recurrence; (4) choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and (5) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. (Fraser, 1974, p. 637)

This definition, therefore, identifies two potential goals of genetic counseling: 1) to transmit medical facts about a particular disorder; and (the more controversial), 2) to help couples make use of this information. The most documented effectiveness of genetic counseling has been in providing patients with information on diagnostic issues, recurrence risks, or both (Kessler, 1992a).

Genetic counselors have diverse educational credentials and clinical experiences. Persons who provide genetic counseling include master's trained genetic associates, nurses, physicians, and social workers.

Two aspects of genetic counseling that "are frequently in tandem, rarely side-by-side, and sometimes in conflict" (Duster, 1990, p. 79). On one hand, the genetic counselor acts as a "neutral" information giver, providing statistical probabilities and risk of recurrence. On the other hand, some

genetic counselors view sympathetic communication between counselor and client as the central concern of good counseling (Duster, 1990). Many genetic counselors also advocate helping clients adjust psychologically and socially to the problem. However, this aspect of genetic counseling tends to be neglected (Fraser, 1974; Sorenson, et al. 1981).

Genetic services are usually located in large, urban tertiary medical centers. Harris (1989) notes that it is not feasible for rural centers to ask individuals to travel distances as far as 350 miles to urban centers for counseling or to send a counselor a similar distance. Some large medical centers have established "satellite" clinics to provide genetic services in rural areas.

Genetic "counseling" is usually a one-time 45 to 60 minute session with an occasional follow-up session. Genetic counselors in prenatal settings usually take an extensive family history and gather information on the pregnancy and possible teratogenic exposure. Couples are told about the available tests and the risks involved in prenatal diagnostic testing. Some patients choose to have prenatal testing and some do not. Those who decide to undergo testing are presented a number of options if their fetus is at risk (including fetal termination). Genetic counselors who work with the pediatric population, try to determine if the presented disorder is genetic in origin. If it is genetic in origin, parents are told about the nature of the disease and

the risk recurrence for future children. In all cases, the primary role of genetic centers is to provide patients with information that enables the clients to make informed decisions (Byman, 1988).

#### Health Education And Genetic Counseling

Health education is any planned educational activity which promotes health or illness related learning (Tones, 1990). Health education which takes place in a medical setting is termed "patient education." Planned patient education programs and services include activities designed to inform patients about their medical condition and to assist patients to manage their disease and to modify their behavior in order to promote health and prevent disease (Squyres, 1985). Regardless of the setting, health education should not seek to coerce or persuade but rather to facilitate informed choice (Tones, 1990).

The critical outcome of a health education intervention is that the client possesses the understanding, skills, and experience needed to make and implement informed health decisions (Shireffs, 1984). There is disagreement, however, as to the methods by which this outcome is best achieved. Effective health education may 1) produce changes in understanding or ways of thinking; 2) bring about some shift in belief or attitude; 3) influence or clarify values; 4)

facilitate the acquisition of skills; and 5) effect changes in behavior or lifestyle (Tones, 1990).

Genetic counseling, in many respects, can be viewed as a form of health education. Counselors usually agree that genetic counseling is basically an educative undertaking and that a primary goal of genetic counseling is client education (Sorenson et al., 1981). Imparting information and understanding the implications of that information for clients is an integral aspect of genetic counseling. Genetic counselors are usually concerned with their educative role. They strongly endorse the importance of helping clients understand the diagnosis, etiology, management, risk of recurrence, and options for dealing with that risk (Sorenson et al., 1981; Kessler, 1992). They are less committed, however, to the tasks of helping clients adjust to, or cope with the disorder. Genetic counselors rarely address important medical topics, such as the prognosis of a disease or disorder, and its treatment (Sorenson et al., 1981).

As an educative activity, Sorenson et al. (1981) found genetic counseling to be relatively ineffective. In their study, 54% of clients given a risk and approximately 40% of clients given a diagnosis were not able to report it almost immediately after counseling. These findings indicate problems both with the counselors' ability to educate clients (including assessing client knowledge and learning readiness, and reinforcing learning) and the clients' ability to learn.

### Theoretical Framework

The philosophical and theoretical issues which affect education also affect health education and, therefore, genetic counseling. There are two broad educational perspectives that influence health education. The pre-Renaissance perspective sees the aim of health education as molding or shaping people in the direction of behavioral changes that lead to an increase in health status. The post-Renaissance perspective is the more popular perspective. It sees the mission of health education as providing individuals with the opportunity to make informed choices about behavior (Bates & Winder, 1984).

Technical expertise is only one element involved in health education and genetic counseling. Health educators believe that different theories of learning are applicable to different situations. Given the high variability in genetic disorders, and the association of these disorders to socially identifiable groups which have their own coping mechanisms, it is impossible to advocate a single method or a particular style of genetic counseling that is most effective (Duster, 1990). Competent health educators are able "to both assess the learner and the learning situation and then proceed to educate on the basis of an effective and appropriate theory of instruction" (Bates & Winder, 1984, p. 39). What is known should be taught in a manner that facilitates understanding of current realities. Health educators aid people in the

solution of their problems, not force them to accept an imposed solution (Association for the Advancement of Health Education, 1992). Health education empowers the client to choose which information to apply and which behaviors to perform in their specific situations.

#### Statement Of The Research Problem

The "educative" and "counseling" functions of genetic counseling are intertwined. Education is not concerned merely with knowledge acquisition. Imparting information and understanding what that information means to clients is an integral aspect of counseling (Sorenson et al., 1981). Genetic counselors do not usually follow-up their clients, nor do they usually have any opportunity, other than their single encounter with a client, to assess their effectiveness. Sorenson et al. (1981) found that support personnel, such as social workers and genetic associates, made no significant or only very small differences in terms of client education. Genetic counseling has been documented to be effective solely on the basis of providing patients with information on diagnostic issues (Sorenson et al., 1981; Kessler, 1992).

In 1973, the Committee on Genetic Counseling sponsored by the National Genetic Foundation Inc., reported that little was known about the optimal methods of delivering genetic counseling (Fraser, 1974). No studies were located in the literature that examined the optimal methods of genetic

counseling. This study seeks to answer the following questions:

1. What are the qualifications and training of professionals in the southeastern United States who provide genetic counseling?
2. What are the current roles (i.e. functions, duties, and contributions) of nurses, genetic associates, and physicians in the genetic counseling process?
3. What are the perceptions of nurses, genetic associates, and physicians regarding what their roles (i.e. functions, duties, and contributions) should be in the genetic counseling process?
4. What are the educational methods used by these health professionals in genetic counseling?

#### Significance Of The Research Problem

One of the leading causes of infant mortality in the United States is congenital anomalies. In 1900, three percent of infant deaths were due to genetic disorders. Today, approximately one-fourth of infant deaths are attributed to genetic disorders (Office of Technology Assessment, 1988). This is due primarily to a reduction in total infant deaths.

Congenital anomalies, when they do not result in death, may cause severe disabilities. Approximately 1 in every 16 infants born in the United States has some form of birth defect and many chronic health problems have a genetic

component. In addition to the personal suffering from the mortality and morbidity associated with birth defects, the economic cost of these disorders to society is quite high. Early identification of people at risk for genetic disorders provides the opportunity to inform and counsel on preventive measures, appropriate treatment, risk recurrence, and family planning.

The increase in genetic technology and the resultant increase in demand for genetic testing, screening and counseling have the potential to overwhelm health care providers. Genetic counseling is still being done primarily by physicians. However, physicians may neither have the genetic knowledge nor the time to keep up with the demand for services (Fraser, 1974). Some counseling problems are so complex that the services of a professional genetic counselor are often required. Currently, there is a shortage of certified genetic counselors in the United States. In the near future, these counselors probably will not be able to keep up with the voluminous information brought about by the new testing and treatment technologies (Duster, 1990).

Genetic counseling is still a relatively new profession. The counseling session is still dominated by presentation of genetic-medical facts and statistical probabilities (Sorenson et al, 1981; Kessler, 1992). The educative aspect of genetic counseling is underemphasized and the health education/patient education methods and techniques are infrequently and

inappropriately used. This study can 1) help programs that train genetic counselors identify ways to emphasize and to incorporate health education/patient education principles, methods, and techniques into their curricula; and 2) help consumers and other health professionals understand the role of genetic counselors.

In this study, states in the Southeastern United States were chosen because 1) this study is part of a larger project that seeks to determine the social, ethical, and legal aspects of genetic screening, testing, and counseling in Florida and Georgia; and Florida and Georgia are included in the southeastern Regional Genetics Group; 2) historically, there has been controversy about sickle cell screening and testing (Duster, 1990); and the large number of African Americans in these states raise some salient issues about genetic screening, testing, and counseling in these states. The results from this study can serve as a pilot for a national study that examines these issues.

#### Assumptions

The basic assumptions of this study are that the participants will honestly and correctly report the required information. It is also assumed that the instrument will accurately assess the research variables.

### Limitations

Data are generated through self-administered surveys, and are, therefore, subject to recall error, and self-report biases. Also the statistical procedures used in the study can only show association between variables; they do not show cause and effect.

The limitations of using a mail survey is the low response rate and the lag time in returning the questionnaire. A possible limitation is that the sampling frame (directories from the southeastern Regional Genetics Group, the National Society of Genetic Counselors, and the American Society of Human Genetics) may not be complete and up to date. The genetic facilities and centers listed in the SERGG directory will be contacted prior to the mailing to verify and update the employment status of persons listed in the directory. Membership in most organizations is usually voluntary and it is probable that some potential subjects are not members in any of the three organizations. Professional organizations provide continuing education opportunities for their members; and membership is usually required to maintain professional certification/licensure. Therefore, it is believed that the majority of individuals who provide genetic counseling in the above listed states will also be members of at least one of these organizations.

### Delimitations

This study will be delimited to genetic counselors in Alabama, Florida, Georgia, Louisiana, North Carolina, South Carolina, and Tennessee who are members of the Southeastern Regional Genetics Group, American Society of Human Genetics, and the National Society of Genetic Counselors. Nationally, medical genetic centers tend to have universal standards and protocols. It is not believed that genetic counselors in this part of the country use different educational and counseling methods and techniques from their national counterparts.

## CHAPTER 2 REVIEW OF THE LITERATURE

### Birth Defects: A National Health Challenge

Improving the health of infants is a national challenge. In 1987, 3.8 million infants were born in the United States; 34,408 of them died before their first birthday (Department of Health and Human Services, 1990).

Congenital anomalies (birth defects) are a leading cause of infant mortality in the United States. One-fourth of all congenital anomalies are caused by genetic factors (Department of Health and Human Services, 1990). Congenital anomalies most likely to be lethal include malformations of the brain and spine, heart defects, and combinations of several malformations (Department of Health and Human Services, 1990). Approximately 1 in every 16 infants born in the United States has some form of congenital anomaly (Duster, 1990); and congenital anomalies account for about one quarter of all infant deaths (Office of Technology Assessment, 1988).

Genetic screening and counseling services are tools that can help the health of the nation's children. There are 23 national health objectives pertaining to maternal and child health, and at least 10 national health objectives of direct concern for geneticists. Three national health

objectives directly pertain to genetic screening and counseling:

1. . . . increase to at least 60 percent the proportion of primary care providers who provide age-appropriate preconception care and counseling. (Department of Health and Human Services, 1990, p. 342)

Preconception identification of couples at risk for offsprings with genetic disorders provides the opportunity to inform and counsel on appropriate treatment, risk recurrence, and pregnancy planning (Department of Health and Human Services, 1990).

2. . . . increase to at least 90 percent the proportion of women enrolled in prenatal care who are offered screening and counseling of prenatal detection of fetal abnormalities. (Department of Health and Human Services, 1990, p. 382)

Prenatal screening is used to identify serious disorders which have long term consequences for infants and their families. This allows for early medical interventions and family planning (Department of Health and Human Services, 1990).

3. . . . increase to at least 95 percent the proportion of newborns screened by State-sponsored programs for genetic disorders and other disabling conditions and to 90 percent the proportion of newborns testing positive for disease who receive appropriate treatment. (Department of Health and Human Services, 1990, 384).

Most states screen for genetic and metabolic disorders and treat or refer for treatment those with a confirmed diagnosis. Screening for phenylketonuria (PKU) and congenital hypothyroidism is virtually universal. Universal screening for sickle cell is recommended, but states with negligible at-

risk populations may choose to target their testing program. Some states also screen for galactosemia (Department of Health and Human Services, 1990).

#### The Human Genome Initiative/Human Genome Project

With the aid of new technologies, prospective parents can discover if their fetus will be affected by a genetic disorder. Though the technology exists for detecting some genetic disorders, much information about the human genome remains to be discovered.

Research efforts aimed at creating genetic linkage and physical maps of chromosomes or entire genomes are referred to as genome projects (Office of Technology Assessment, 1988). There are many international genome projects. The United States' HGI is the largest and most ambitious research in the history of biology (Dickson, 1989; Office of Technology Assessment, 1988; Watson and Cook-Deegan, 1990). The 15-year HGI efforts aim 1) to acquire complete knowledge of the organization, structure, and function of the human genome, 2) to map and sequence the 3 billion base pairs that make up the human genome, 3) and to construct common resources for the study of human genetics (Dawson & Singer, 1990; Dickson, 1989; Goodman, 1990; Office of Technology Assessment, 1988; Watson & Cook-Deegan, 1990).

The HGI in the United States is funded by the Department of Energy (DOE) and the National Institutes of Health (NIH)

National Center for Human Genome Research (NCHGR) (Office of Technology Assessment, 1988; United States Department of Energy, and Office of Energy Research, Office of Health and Environment Research, 1992). The DOE's involvement in the project stems from a congressional mandate to monitor inherited damage caused by exposure to radiation and other environmental hazards (Cantor, 1989). The DOE will focus on mapping the genome, developing the sequencing technologies and instrumentation, and collecting and analyzing data. The DOE also will study the ethical, legal, and social issues arising from the use of data generated by the project (Roberts, 1991; United States Department of Energy, and Office of Energy Research, Office of Health and Environment Research, 1992). The NIH will map and sequence the genomes of model organisms, ranging from yeast to the mouse (Roberts, 1991). Many genes are conserved among model organisms, and it is easier to study and eventually understand them in yeast than in human (Roberts, 1991). The completion of physical maps of Escherichia coli showed the feasibility of this project (Cantor, 1989).

In October, 1991, scientists began work on the project's first stage. This stage, to be accomplished in five years, is to generate a physical map of the human genome (Dawson and Singer, 1990; Goodman, 1990). The fundamental physical and functional unit of heredity is the gene; and the chemical bearer of genetic information is deoxyribonucleic acid (DNA).

The DNA of humans is associated with protein in chromosomes. The genome of an organism is the entire complement of genetic material in the set of chromosomes (Office of Technology Assessment, 1988).

Human DNA consists of a sequence of 3 billion pairs of nucleotide bases. Each normal human carries 46 chromosomes. Forty-four of these are paired into twenty-two sets of identical chromosomes, called "autosomes." Each parent contributes one-half of the twenty-two sets. In addition, there are two sex chromosomes, called "X" and "Y" chromosomes. Each parent provides a single sex chromosome to the fetus. Males usually have one X and one Y chromosome; and females usually have two X chromosomes. When the proposed physical map is completed, it will include the DNA of each of the 24 chromosomes with their identifying markers (Dawson & Singer, 1990; Duster, 1990; Office of Technology Assessment, 1988).

The second stage of the project is to sequence the DNA between the markers on the physical map and to define the function of all the genes in human DNA. (Dawson & Singer, 1990). This stage will probably take twice as long as the first. It will assist biomedical researchers in their assault on diseases through more effective methods of detecting disease, and hopefully, through development of effective therapies based on improved understanding of disease mechanism (Office of Technology Assessment, 1988). The new technologies will also help in the assessment of public health needs by

permitting the detection of mutations following exposure to radiation or environmental agents. Information about DNA sequences is essential if we are to understand the genetic basis of inherited diseases such as Duchenne's muscular dystrophy and Huntington's disease, and chronic illnesses such as heart disease and cancer (Dawson & Singer, 1990; Watson & Cook-Deegan, 1990). Advances in this technology have already provided insights into the origins of diseases such as sickle cell disease, hypercholesterolemia, and hemophilia (Office of Technology Assessment, 1988).

Deeply rooted beliefs about the political and moral neutrality of scientific discoveries have tended to preclude social debate about the role of power in determining and applying scientific knowledge (Duster, 1990; Nelkin & Tancredi, 1989). As genome projects are undertaken, their long range social and ethical implications need to be considered as part of policy analysis (Office of Technology Assessment, 1988). Ethical questions about personal freedom, privacy, and societal versus individual rights of access to genetic information are among the most important ones raised by the HGI. The potential uses and abuses of the biological information to be gained from the HGI also raise many concerns.

The main social concern is that eugenics programs will be reincarnated (Duster, 1990; Nelkin and Tancredi, 1989). The term "eugenics" refers to the prevention of reproduction of the unfit and the encouragement of reproduction of the fit (Ludmerer, 1972). At the beginning of this century, with the rediscovery of Mendel's classic paper of 1866, many scientists began to look at its social impact and potential applicability to social problems (Ludmerer, 1972). The work of American geneticists and eugenicists was not easily distinguished during this era (Duster, 1990).

Eugenicists possessed a racial as well as a class bias. They were evolutionists who regarded the Anglo-Saxon or "nordic" race as nature's "fittest race" (Ludmerer, 1972). The stage was set for this movement by the eighteenth and nineteenth century idea of human perfectibility and from Darwin's work on the survival of the fittest. As a response to eugenic ideals in the United States, the Eugenics Record Office was started at Cold Spring Harbor, Long Island, New York, in 1910 (Haller, 1963; Ludmerer, 1972).

The German eugenics movement also began at the turn of the century. With the advent of Hitler, the eugenics movement in Germany was inextricably interwoven with the Nazi regime (Ludmerer, 1972). Ideas of race and or Aryan superiority were fundamental components of the Nazi culture. In 1933, Hitler decreed the Hereditary Health Law, or Eugenic Sterilization Law, which was designed to ensure that "inferior genes" were

not passed down to members in the Third Reich (Ludmerer, 1972).

In the United States, many eugenicists were able to influence social policy; and in 1924, the United States passed a law that regulated the racial and ethnic composition of its immigrants and sealed its racial and ethnic composition (Duster, 1990). The United States rationalized the use of eugenic ideals in setting immigration quotas in order to improve and enhance the "perfect society." This was the new eugenics. Today, geneticists such as Margaret Shaw (1984) believe that the law should control the spread of genes that cause severe deleterious effects.

Duster (1990) is concerned that the eugenics of the latter part of this century will "not come through the front door, as with Hitler's Lebensborn project. Instead "it will come by the back door of screens, treatments, and therapies" (p. x). To date, hundreds of genetic markers indicating predispositions to hereditary diseases have been identified. In addition, there have been increasing studies on the genetic basis on phenomena such as mental illness, alcoholism, and crime (Duster, 1990; Nelkin & Tancredi, 1989). These studies may someday be the basis for preventive or therapeutic actions. However, the potential exists for misuse by schools and third party payers such as insurance agencies and employers (Nelkin & Tancredi, 1989).

HGI research is fully funded by the federal government and is very costly. In 1991, the project's budget was \$135 million, \$87 million of which went to the NIH (Roberts, 1991). The major concern with the funding of the HGI is that a large portion of these funds came from a redistribution of NIH funds, funds that support other biological and medical research (Sillence, 1990). Another concern is the commercial value of genome sequences which has already been recognized by companies that have applied for patents on a number of specific materials and techniques (Office of Technology Assessment, 1988). The Office of Technology Assessment (1988) has noted that:

. . . the potential loss of critical data held by private parties, the duplication of effort, and the control of knowledge raise serious questions about a combined scheme of public versus proprietary holding of fundamental knowledge. There is a strong argument that parts of research that are funded publicly should yield public information, while allowing scientists and others to retain the benefits of commercial exploitation of inventions. (p. 83)

The DOE has set aside three percent of its budget to study and analyze the social, ethical, and legal implications of genome research (Watson & Cook-Deegan, 1990).

#### Health Education

The field of health education is the applied social science concerned with behavioral and lifestyle aspects of human disease (Bates & Winder, 1984). It is concerned with voluntary changes that affects status and has rejected the

traditional public health prescriptive of "should do or ought to do" (Green, 1976; Bates & Winder, 1984).

Health education is the term used to describe the planned use of educational processes to attain health goals (Bureau of Health Education, 1978). Health education attempts to close the gap between what is known about optimal health practice and that which is actually practiced. Green & Kreuter (1990) defines health education as "any combination of learning experiences designed to facilitate voluntary actions conducive to health" (p. 17). This definition: 1) emphasizes the importance of matching the multiple determinants of behavior with multiple learning experiences; 2) distinguishes health education from incidental learning experiences; and 3) emphasizes voluntary means without coercion.

Issues of concern to education also are related to health education (Association for the Advancement of Health Education (AAHE), 1992). Education is not concerned merely with the acquisition of information. The individual is expected to apply that information in order to develop responsible personal, family and collective behaviors (AAHE, 1992). Health education also goes further than the provision of information. The Bureau of Health Education (1978) notes:

. . . while health education includes acquiring knowledge about health matters, its purposes is the use of that knowledge. It addresses the formation of values, the acquisition of decision-making skills and the adoption or reinforcement of desirable health practices. Health education honors individuals' right to privacy, their right to meaningful information, and their right to make their own choices. (Health Education Bureau, 1978, p. 4)

Health education contributes to the total education of the individual by providing meaningful experiences which can positively influence health behavior and facilitates the primary prevention of health problems (Green and Kreuter, 1990). Health educators assist the client in making informed decision about health and provide them with the skills to implement the decision.

Today's chronic diseases do not lend themselves to passive measures of prevention. Health education aims to decrease, eliminate, or modify negative health behaviors and to foster those that positively influence health. Derryberry (1952) stated that the aim of health education:

. . . is to help people to achieve health by their own actions and efforts. Health education begins therefore with the interests of people in improving their conditions of living and aims at developing sense of responsibility for their own health betterment as individuals, as members of families, communities or governments. (p. 1)

Some health educators view the ultimate goal of health as liberating an individual's potential strengths so that personal actions become deeply satisfying and constructive (AAHE, 1992; Greenberg, 1978; Walker & Bibeau, 1986). Greenberg (1978) proposes that the task of health education is "to free people so that they make health-related decisions based upon their needs and interests as long as these needs and interests do not adversely affect others" (p. 20). This view of health education respects the human being's consciousness and cultural dynamics which is necessary for

understanding health in a democratic society (Walker & Bibeau, 1986).

Health education shares the philosophical perspective of public health that health is a personal and societal issue and that planned social change is both useful and desirable when it promotes the public good (AAHE, 1992; Bates & Winder, 1984). This philosophy means that people may be asked to alter their lifestyles for the larger "public good" (Bates and Winder, 1984). AAHE states:

" . . . health education as both process and program, influences individual, family and societal development, knowledge, attitudes and behavior. It seeks the improvement of individuals, family and community health" (AAHE, 1992 p. 4)

Thus, another goal of health education is to provide consumers with the skills to judge messages in terms of their potential benefit to self and society (AAHE, 1992). The two main challenges to health education is 1) maintaining the individual's freedom while achieving desirable social ends; and 2) changing individual and group behavior while reinforcing individual responsibility (Bates & Winder, 1984).

The critical outcome of a health education intervention is that the client possess the understanding, skills, and experience needed to make and implement informed health decisions (Shireffs, 1984). Effective health education may 1) produce changes in understanding or ways of thinking; 2) bring about some shift in belief or attitude; 3) influence or

clarify values; 4) facilitate the acquisition of skills; and 5) effect changes in behavior or lifestyle (Tones, 1990).

### Genetic Counseling

Genetic counseling is the current approach to educating and perhaps preventing many genetic diseases (Griffiths, 1983). Imparting information and understanding what that information means to clients is an integral aspect of genetic counseling (Kelly, 1986; Sorenson 1981). Therefore, genetic counseling can be viewed as a form of health education, and the philosophical and theoretical issues which affect health education also affect genetic counseling.

Kelley (1986) views the purpose of genetic counseling as the maximal use of medical technology to reduce the incidence of genetic disorders, and hence, the financial impact on society. Shaw (cited in Lubs & de la Cruz, 1977) suggests that the two broad aims of genetic counseling are: 1) to promote societal goals by encouraging rational decision making, and 2) to protect individual autonomy by encouraging counselees to make their own decisions, whether rational or not. Shaw's outline of the objectives of genetic counseling is presented in Table 2-1.

There are numerous definitions of genetic counseling. March of Dimes Birth Defects Foundation (1980) defines genetic counseling as follows:

. . . genetic counseling provides and interprets medical information based on expanding knowledge of human

genetics, the branch of science concerned with heredity. Its major goal is to convey understanding of birth defects to affected families and enable prospective parents to make informed decisions about childbearing. (p. 5)

According to this definition, what is called "genetic counseling" can have either of two foci. First, genetic counseling can concentrate almost exclusively on transmitting medical-genetic information. If that is the case, Sorenson et al. (1981) note that genetic counseling would be better defined as a "medical-genetic consult or seeing a medical geneticist" (p. 144). Second, genetic counseling can focus on the broad range of psychosocial and emotional issues that are presented in the counseling session. Genetic counselors who accept a larger definition of their role will focus on both of these aspects (Kelley, 1986; Sorenson et al. 1981).

Kelley defines genetic counseling as:

. . . an educational process that seeks to assist affected and/or at risk individuals to understand the nature of the genetic disorder, its transmission and the options available to them in management and family planning. (p. 343)

Kelley (1986) believes that other definitions suggest a counseling role beyond the expertise of most genetic counselors and make unrealistic demands on them.

Fraser (1974) offers a more comprehensive definition of genetic counseling:

. . . genetic counseling is a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or the family to (1) comprehend the medical

facts, including the diagnosis, the probable course of the disorder and the available management; (2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and (5) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. (Fraser, 1974, p. 637)

This definition provides a broad and complex mandate for genetic counseling and is almost exclusively oriented to genetic counseling as a multidisciplinary team approach. This definition provides a useful perspective on how genetic counseling is viewed by many providers today (Sorenson et al. 1981).

Experts distinguish among genetic counseling, genetic diagnostic procedures, and clinical management of the disease. For example, amniocentesis and CVS are prenatal diagnostic procedures; biochemical or cytogenetic tests are diagnostic; taking a family history and discussing the implications for future pregnancies is genetic counseling; and pregnancy termination is clinical management (Fraser, 1974). It is almost impossible to draw a line as to where diagnostic procedures stop and genetic counseling begins (Fraser, 1974).

Kelley (1986) identifies six elements of genetic counseling:

1. Understanding of the Natural History and Treatment of the Disorder Under Consideration. The extent of this

discussion will depend on the counselee's prior knowledge and experience with the disorder.

2. Understanding the Applicable Genetics. The particular mechanism by which the genetic disorder may follow a familial pattern and modes of inheritance are discussed.
3. Understanding of the Risks in Probabilistic Terms. The risk of disease recurrence is discussed in numerical terms.
4. Understanding of the Available Options. The couple is provided with a list of available options and the merits of each option is discussed. These may include having no further children, taking a chance, adoption, abortion, and artificial insemination.
5. Assistance with Decision Making. The role of the counselor is to provide the couple with factual information and help them through the decision-making process but not direct their thinking along a particular course of action.

Table 2-1 Genetic Counseling Objectives

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- A. Directed at the affected individual
  - 1. Decrease the pain and suffering of the disease
  - 2. Advise if treatment is possible
  - 3. Quote risk figures for offspring and other relatives
  - 4. Reduce anxiety and guilt
  - 5. Help patient cope with affliction
- B. Directed at the parents
  - 1. Help couples make rational decisions about their reproduction
  - 2. Give family planning options to at-risk matings
  - 3. Reduce anxiety and guilt in parents
  - 4. Educate the parents about the disease in question
  - 5. Discourage high-risk couples from making their own decisions
  - 6. Discourage high-risk couples from reproducing
- C. Societal goals
  - 1. Eliminate genetic disease
  - 2. Prevent genetic disease
  - 3. Reduce the incidence of genetic disease
  - 4. Reduce the burden of genetic disease
  - 5. Decrease the frequency of deleterious genes
  - 6. Upgrade awareness of genetics in the public
  - 7. Influence mate selection

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Source: Lubs and de la Cruz, 1977, p. 36.

6. Assistance in Proceeding with the Selected Options. The counselor ensures that the couple receive the necessary professional referrals.

Counseling refers to "any person-to-person relationship in which helpers know their own limits, provide what assistance they can, and are able to recognize situations requiring services beyond their ability to render" (Litwack et al., 1980). Litwack et al. believe that all counseling is health counseling because counseling enables individuals to promote their own well-being, which involves emotional, intellectual, physical, social, and spiritual health.

As with health counseling, genetic counseling generally takes one of two approaches, directive and nondirective (Kelley, 1986). Directive counselors usually recommend a course of action, in addition to presenting the medical facts. They may also direct the couple's choice through a preconceived limitation on options from which the couple might choose (Kelley, 1986).

In nondirective counseling, genetic counselors do as much as possible to not communicate their personal opinions, prejudices, and biases concerning what decision a couple should make (Duster, 1990). Nondirective counseling assumes that the couple is free to make their own decisions based on understood risks and options and that the role of the

counselor is educational. This latter approach is the recommended for use by genetic counselors (Kelley, 1986).

Although the nondirective counseling approach is recommended, some practitioners advocate a directive approach, even suggesting whether a couple should or should not bear children (Emery, 1977; Falls, 1959; Fuhrmann & Vogel, 1969; Kallman, 1959; Townes, 1970). Some genetic counselors have indicated that directive counseling may be appropriate under some circumstances. Czeizel et al. (1981) suggest that whether one uses the directive or nondirective approach may depend on (1) the general needs of the clients; (2) the couple's education, gender, age, etc.; (3) the actual possibilities (e.g. the time and atmosphere); (4) the legal protection of the counselor; and (5) the efficiency of the counseling.

Czeizel et al. (1981) used directive counseling, which they called "information-guidance," in a family planning clinic in Hungary to deter women who were at moderate or high risk for delivering a child with a genetic disorder. The recommendations made to women who wanted a child or further children were based upon: 1) the burden of expected disorders; 2) the possibilities of treatment; 3) the possibility of prenatal diagnosis; 4) the specific genetic or teratogenic risk; 5) the socioeconomic conditions of the family; and 6) the maternal risk during pregnancy. Based on the above guidelines, this study found a high deterrent rate among women

whose future pregnancies needed serious consideration or were not recommended.

In their study, Somer et al. (1988) found that although the counseling was aimed at being as nondirective as possible, a considerable proportion of the counselees felt that some type of recommendation had been given. Twenty-five percent of the respondents stated that they had been encouraged to have (more) children, whereas two percent felt that they had been told not to do so. Forty-two percent of the respondents reported that they wanted to know the medical facts, as well as the counselor's/physician's opinion. The researchers noted that many families may still expect the counselor to assume the traditional role of the physician by advising patients on what actions to take. Others wanted to hear what decisions other families have made in a similar situation.

In 1969, the World Health Organization recommended a neutral presentation of recurrence risk and other medical facts as well as follow-up to evaluate whether advice given had been followed (Shaw, 1977). Griffin (1983) notes that "neutral" and "advice-giving" are not seen as contradictory among genetic counselors. Griffin (1983) attempts to explain this apparent contradiction by stating that counselors are indeed directive with a preventive goal, but due to their clinical orientation they see prevention as beneficial to those counseled, and perhaps only marginally beneficial to society.

Clarke (1991) claims nondirective genetic counseling is "a sham, not because of a personal failure on the part of the genetic counselor but as a direct structure of the encounter between counselor and client" (p. 998). Clarke contends that an offer of prenatal diagnosis implies a recommendation to accept that offer, and a tacit recommendation to terminate a pregnancy if any abnormality is found. "This sequence of events is present irrespective of the counselor's wishes, thoughts and feelings because it arises from the social context rather than the personalities involved" (Clarke, 1991, p. 1000).

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) states:

. . . despite its history and rationale, nondirective counseling is challenged on a number of grounds. first, genetic counseling is being drawn more closely into the practice of medicine, and the emphasis on nondirectiveness contrasts with traditional medical practice, in which physicians are more likely to suggest which course of action they consider preferable. Second, some people who receive genetic counseling exert pressure toward directiveness. (p. 37-38)

Counselors should be able to distinguish between a real breakdown in the counselee's reasoning ability and poor judgement (The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). The commission also cautions counselors against treating as "irrational" any counselees' decision with which they disagree. Principles of genetic counseling developed by

genetic counselors at a workshop at Sarah Lawrence College are given in Table 2-2.

The gender of the counselor may influence the counseling approach, the counseling process and perhaps its outcome (Wertz & Fletcher, 1988; Zare, 1984). Wertz & Fletcher found male counselors favored more directive approaches to counseling than female counselors. Males were 1.9 times more likely than females to consider it appropriate to inform client what most other people have done; 4.6 times more likely to consider it appropriate to inform clients what they would do in their situation; and 6.9 times more likely to advise clients what to do.

In 1973, the National Genetics Foundation reported that the optimal methods of delivering genetic counseling services was not known (Fraser, 1974). These optimal methods are still not known. However, In 1989, participants at a workshop at Sarah Lawrence College offered principles and concepts that should govern the choice of techniques and content of genetic counseling sessions (see Table 2-2).

Table 2-2 Principles of Genetic Counseling

- 
1. Educate the patient about what to expect in a genetic counseling session:
    - a. explain to the patient how genetic counseling differs from other medical advice-giving
    - b. introduce the concept of nondirectiveness
    - c. identify the "patient " as the family, not just the individual
    - d. contract with the patient
    - e. describe the ingredients of the genetic evaluation
    - f. establish the potential for either a short- or long-term contact allowing for flexibility
    - g. acquaint the patient with the notion of genetic counseling as a comprehensive service including medical, educational, and psychosocial aspects
    - h. establish the role of the patient as the decision-maker
  2. Recognize the aspects of "crisis" inherent in the diagnosis of a genetic or potential genetic condition:
    - a. be emotionally and physically available during crisis periods
    - b. acknowledge and address the stress of the situation
    - c. plan support for events anticipated to be anxiety-provoking
    - d. prepare the patient in advance for the possibility of uncertain or shocking information
    - e. relay information in a timely manner
    - f. gather resources and tools for diagnosis and supportive counseling in advance of a crisis whenever possible

Table 2-3--continued

- 
- g. utilize one's experience of dealing with families in a similar situation to advise individuals/couples of ways that they might successfully cope with the crisis. (This does not mean advising people as to what decisions they should make).
  3. Cooperate with other medical personnel and specialists to ensure the correctness of the diagnosis and that accurate information is given to the patient:
    - a. obtain a complete and accurate family and medical history
    - b. review medical records with appropriate specialists
    - c. consult with colleague to obtain relevant tests, examinations, etc.
    - d. use multiple sources of medical information
  4. Address the patient's concerns about reproductive decisions and options and planning for child-rearing:
    - a. provide accurate and complete information about the natural history of the condition in question
    - b. identify the reproductive options available to the individual/family and put them in a personalized context
    - c. help the patient to hypothesize a variety of outcomes based on possible family planning decisions and to evaluate the impact on the entire family
    - d. help the patient to recognize and understand the emotional, cultural, and religious factors that may influence decision-making
    - e. clarify the patient's understanding of probability
  5. Provide support for the patient who is dealing with situations outside his/her previous range of experience:

Table 2-3--continued

- 
- a. normalize the patient's feelings by being non-judgmental and by comparing the patient's feelings and responses to those of others who have been in similar circumstances
  - b. provide anticipatory guidance to the patient by drawing upon one's experience with other individuals, but also by articulating one's recognition of individual differences in the ways people deal with similar situations
  - c. identify and reinforce coping strategies and introduce new strategies where necessary
  - d. help the patient to organize and anticipate feelings and emotional tasks
  - e. help individuals to identify similarities between the "new," stressful situation and other more familiar and "normal" occurrences
  - f. help family members to communicate in a constructive way in order to facilitate resolution of differences and maximize mutual support
  - g. help the patient to identify to identify his/her own support systems and to utilize them in a constructive way
6. Recognize and explore the emotions inherent in the genetic counseling process:
- a. understand the source of anger and help patients to recognize and resolve it
  - b. differentiate between the anger of the patient toward his/her situation that may be projected to medical personnel and anger that is justifiably directed at health professionals because of deficits in care (including the genetic counselor)
  - c. provide an environment that allows the patient to express any and all emotions
  - d. help couples to understand the different, but legitimate, ways in which they may respond to situation

Table 2-2-continued

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- e. explore the emotional content of medical and statistical information
  - f. explore the emotional milieu in which decisions will be made and the emotional factors influencing those decisions
  - g. assess the need for further supportive counseling by other mental health professionals
  - h. utilize the expertise of other health professionals as a resource for improving one's own handling of the patient's emotions
  - i. alleviate feelings of guilt and anxiety
  - j. explore the psychological history of the patient in an effort to appreciate
  - k. give "permission" to the patient to feel and express negative feelings
  - l. provide a flexible "timetable" that will give the patient and idea of how he/she may expect to feel following the event in question
  - m. include in this "schedule" the notion that the patient will feel better, that he/she will not always feel this way, but that it is O.K. to feel terrible now
  - n. help patient to recognize that even though he/she may not feel that he/she is coping, there may be ways in which he/she is actually coping quite successfully
7. Facilitate decision-making
- a. facilitate communication between partners and/or other members of a family
  - b. identify and utilize familiar family communication patterns
  - c. elicit from the patient his/her preferred course of action and help him/her to move toward implementing this course

Table 2-2--continued

- 
- d. help the patient to identify all factors that will influence the decision-making
  - e. recognize the difficulty of making decisions in the face of uncertainty or ambiguity
  - f. help members of a couple understand their differences and come to a mutually acceptable decision if possible
  - g. address the uncertainty a patient may have about a particular course of action or a decision
8. Respect the autonomy and decision-making capacity of the patient:
- a. establish the patient's role as a partner in the genetic counseling process/case planning
  - b. assume a nondirective stance in the decision-making process
  - c. refuse to answer the question, "What would you do if you were in my shoes?"
  - d. help patients arrive at decisions that are consistent with their own value systems
  - e. support the patient's belief that he/she is the one best suited to make whatever decisions are appropriate
  - f. help the patient to accept that he/she has made the best decision for him/her given the available information, options, and personal values
  - g. respect the patient's right to his/her own medical information and the right to a complete explanation of the relevant facts
  - h. respect the patient's wishes concerning who should participate in the genetic counseling sessions
9. Respect the patient's experience, knowledge, and values as valid bases for decision-making:
- a. elicit the patient's personal experience of medical events

Table 2-2-continued

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- b. learn from each patient and, in turn, educate other health professionals
  - c. avoid presumptions about the patient's experience and/or point of view
  - d. remain open to the patient's correction of one's own perception of the situation
  - e. elicit the patient's interpretation of the situation and accept the validity of the interpretation, even if it differs from one's own
  - f. utilize the patient's own terminology
  - g. use feedback from the patient to assess and revise the counseling approach
  - h. encourage the patient's active participation in determining the pace and process of counseling
  - i. elicit from the patient cultural influences on the decision-making process and coping strategies
  - j. understand the ways in which a marital or other significant relationship influences the decision-making process
  - k. appreciate the ways in which other important losses may affect the ability to make decisions and to cope with the current situation
10. Adapt the giving and gathering of information to the individual needs of the patient:
- a. elicit the patient's knowledge about the condition/situation before giving information
  - b. learn something about the emotional, educational, social, and cultural background of the patient before giving information, and utilize terminology that is comprehensible to him/her
  - c. allow the patient to control the specific information he/she receives and the time frame within which he/she receives it

Table 2-2--continued

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- d. adapt the information-giving to the individual needs of the patient with respect to its emotional content and potential impact on the family
  - e. communicate genetic concepts in comprehensible terms, with patience and repetition, and utilize diagrams and other more innovative methods to illustrate these concepts
  - f. assume that the patient is competent to understand the information if it is communicated in an appropriate manner, and that it is the responsibility of the counselor to make him/herself understood
  - g. address the patient's expressed concerns for information at the beginning of the information-giving period if at all appropriate
11. Act as advocate for the patient
- a. educate other health professionals about the needs of patients with genetic disease
  - b. act as liaison between the patient and outside agencies or educational institutions to ensure optimal care for the patient
  - c. intervene, wherever possible, to minimize the emotional discomforts of patients undergoing various procedures such as prenatal diagnosis or termination of pregnancy
  - d. cooperate with other health professionals to alleviate emotional distress at the time of a loss or painful diagnosis
  - e. convey to patient one's willingness to advocate on their behalf
12. Work consistently toward empowering patients to make autonomous decisions and to advocate on their own behalf
- a. reinforce existing skills and problem-solving strategies
  - b. encourage patients to generate solutions and test them

Table 2-2-continued

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- c. give patients an opportunity to test their self-advocacy skills prior to implementing them in a "real" situation
  - d. help patients to identify advocacy roles that are manageable for them
  - e. express confidence in the patient's ability to be a successful advocate
  - f. address the patient's anxiety about being an advocate
13. Maintain surveillance over one's own biases and values:
- a. be aware of the ways in which one's own biases and values may interfere with recognizing the autonomy of the patient
  - b. be aware of the ways in which one's own experience and emotional conflicts may influence the giving of information
  - c. discuss troubling cases with associates whenever possible to retain an objective point of view
  - d. probe one's own psyche for clues to unconscious biases
  - e. recognize the differences between oneself and the patient that might interfere with the counseling process
  - f. articulate, if necessary, to the patient some of these differences and reassure patient that these differences need not adversely influence the counseling nor the quality of care
  - g. encourage the patient to be open about his/her feelings of being coerced or directed
  - h. assume a nondirective stance with respect to the patient's decision making
14. Utilize an interviewing format that is designed to take account of all the aforementioned principles:
- a. ask open-ended questions

Table 2-2-continued

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- b. allow questions to reflect one's wish to understand the patient
  - c. employ questions that do not covertly or overtly express one's own presumptions about the patient or the situation
  - d. ask questions that demonstrate one's awareness that there are potentially many different possible answers
  - e. choose language carefully to avoid unnecessary anxiety-provoking emotional content
  - f. take cues from the patient with respect to his/her preference for specific terms
  - g. encourage a dialogue with the patient rather than engaging in a one way "teaching" format
  - h. respond openly to questions asked by the patient
- 

Source: March of Dimes, 1989, pp. 137-142.

### Genetic Counselors

Genetic counselors have diverse educational credentials and background experiences. Persons who provide genetic counseling include master's trained genetic associates, nurses, social workers, and physicians (Kelley, 1986; National Society of Genetic Counselors, Inc., 1991). Genetic counseling is still primarily done by physicians, not by master's trained genetic counselors (Kelley, 1986; Sorenson, 1981).

In a survey of 203 genetic counselors, Sorenson (1981) found the largest percent of counselors (58.6 %) were physicians. An additional 8% held MD/PhD degrees. Thus, about two-thirds of the counselors held medical degrees. The second largest group of counselors (19%), held master's level genetic associate degrees. It can, therefore, be inferred that genetic counseling is very much a medically based activity, practiced mostly by medically trained professionals. In order to maximize their effectiveness as genetic counselors, Davis (1984) suggests that MD/PhD geneticists obtain a full psychosocial history to gain appropriate insights into the prospective counselee's expectations, emotional state, cultural beliefs, level of education, economic status, and family structure.

Nurses deliver more community and maternal child health services than any other group of health care providers (Schmerler and DeConstanzo, 1992). The nurse's role in the

care of a family with a genetic disorder include: 1) screening; 2) assessing both physical and psychosocial responses; 3) referring to supportive services; 4) providing direct care; 5) diet counseling; and 6) teaching the child, family, and other health professionals (Feetham, 1984). Course work in human genetics is absent from the nursing curriculum, and information on genetics is only sporadically offered in nursing education (Feetham, 1984). Mertens et al., (1984) reported that 96.5% of nurses had less than 10 hours of genetics in their curriculum; and 70% of nursing instructors never had a college-level genetics course. However, Feetham notes that most nursing education does include content and practice emphasis on the psychosocial/counseling aspect of care. Feetham suggests that any deficient needs in the nursing curriculum can be met through continuing education, supervised clinical experiences, and didactic content in degree programs at the graduate or undergraduate level.

As part of the genetic team, the social worker focuses on the psychosocial aspects of genetic counseling, assesses social service needs, makes appropriate referrals, acts as a case manager, and offers crisis intervention during exacerbation of the disorders and during the terminal stages of bereavement (Rauch, 1988). Since courses in human genetics are not part of the social work curriculum, it is recommended that 1) all graduate social workers have a working knowledge of genetic diseases, their etiology, and their

consequences; 2) graduate schools of social work develop core curriculum and field practice experience in human genetics; and 3) continuing education areas in genetics be offered regularly (Bishop, 1984).

Until the early 1970s, physicians with an interest in genetics or PhD geneticists with an interest in medicine were the professionals who almost exclusively provided genetic counseling (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). In the 1970s, genetic counselors/genetic associates with master's degrees emerged in response to a substantial increase in demand for screening and counseling. It was found that genetic associates could successfully provide many of the genetic services--history, pedigree construction and analysis, literature review, counseling, education, and referral--once supplied by physicians (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983; Rollnick, 1984).

The first master's degree genetic counseling program was founded at Sarah Lawrence College in Bronxville, New York in 1969. The goals of the program were to develop a cadre of trained clinical genetic counselors and to make the delivery of genetic services more efficient (Rollnick, 1984). Currently, 16 training programs in the United States and one each in Canada, England, and South Africa offer Master's of Science degrees in genetic counseling. There are four

programs that offer a clinical nurse specialist in genetics tract within a master's level nursing program. Mt. Sinai Hospital in New York offers a genetic counseling certification program for individuals who already hold a master's or doctoral degree in a related field (National Society of Genetic Counselors, Inc., 1991).

Programs that train master's level genetic counselors require fundamental preparation in the basic principles of molecular and human genetics, and understanding of the phenotypic expression of human hereditary diseases (Marks, 1984). In addition counselors must have a sound foundation of knowledge about genetic disorders, how they are diagnosed, how they are transmitted, and the clinical implications of specific disorders. They also must be skilled in transmitting this information in a meaningful way (Marks, 1984). A two-year Human Genetics Program curriculum from the Sarah Lawrence College is shown in Table 2-3.

The varied training and background of persons who do genetic counseling led to a certification process. The American Board of Medical Genetics administers separate tests for several categories of genetic professionals, including Ph.D. geneticists, medical geneticists, medical geneticists, and genetic counselors (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). Ninety-nine are certified by the American Board of Medical Genetics or are eligible for certification.

Table 2-3 Human Genetics Program--Sarah Lawrence College

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Mendelian and Molecular Genetics or Seminar in Human Genetics	1 semester
Human Physiology and Anatomy	2 semesters
Biochemistry	1 semester
Lab Techniques in Human Cytogenetics and Human Biochemical Genetics	1 semester
Introduction to Medicine	1/2 semester
Medical Genetics	2 semesters
Issues in Genetic Counseling	3 semesters
Seminar in Technique of Genetic Counseling	2 semesters
Client Centered Counseling	1 semester
Fieldwork	4 credits (200 hours)
Supervised Clinical Training	8 credits (400 hours)

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Source: Marks, 1984, p. 23

There are 725 full and associated members in the National Society of Genetic Counselors (National Society of Genetic Counselors, Inc., 1991). Ninety-nine percent of these are females and 95% are white (Robertson, 1990). The preparation and training of these counselors, as well as their ethnic and socioeconomic status, may affect the counseling process and the meaning and salience of the information provided to the counselees (Kessler, 1992a).

Many genetically determined disorders are expressed in such a limited manner that genetic counseling and medical care are provided by a single medical specialist. For example, "families with hemophilia or sickle cell disease usually are counseled by a hematologist, and those with isolated congenital heart disease by a cardiologist" (Kelley, 1986, p. 347). Master's trained genetic counselors can enhance the quality of counseling by acting as consultants and educational resources to these medical specialists who also provide counseling (Kelley, 1986).

No single individual can provide appropriate genetic counseling in all, or even most, situations (Kelley, 1986). Many genetic counselors are a part of a multidisciplinary team that may include clinical geneticists, pediatricians, obstetricians, neonatologists, social workers, and nurses (Kelley, 1986; National Society of Genetic Counselors, Inc., 1991). Though some overlapping of roles occur, each discipline offers a different clinical perspective and

provides different insights to the counseling process (Davis, 1984). A team approach to genetic counseling has many advantages:

1. It provides a comprehensive approach to diagnosis and treatment.
2. It is convenient for the family and is less disruptive of the family's work and other routine.
3. It facilitates communication among the team members, decreases duplication of services, and increase efficiency or care and implementation of services.
4. It increases the quality of care provided to patients (Chin & Falk, 1990).

If a team approach is used, then the team members' roles should be clearly delineated from the start (Davis, 1984).

#### Role Of The Genetic Counselor

Genetic counselors have two basic roles: information giver and sympathetic supporter (Sorenson et al., 1981; Kelley, 1986; Duster, 1990). The information-giving function is at the heart of genetic counseling. As information-giver, the genetic counselor usually educates the counselees on risk recurrence, diagnostic issues, or both (Kessler, 1992a). The emphasis on information-giving is based on the idea of "nondirectiveness" (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). In legal terms, the genetic counselor must

provide all information to a client that would constitute an "informed decision" (Duster, 1990; Rapp, 1988).

Large amount of genetic information will be generated from the HGI. Genetic counselors are qualified to evaluate how genetic information can be used and abused by government, insurance companies, employers, and other special interest groups (Resta, 1992). They also determine what sort of information and how much information a couple needs and can use, as well as the form in which they can best use it (Kelley, 1986; Rapp, 1988). Consequently, "the genetic counselor really is the gatekeeper between science and social experience, regulating both the quantity and quality of the information on which decisions will be made" (Rapp, 1988, p. 154).

The role of genetic counselor as sympathetic supporter, moral advisor, or psychotherapist is usually controversial (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). According to Webster's Ninth New Collegiate Dictionary (1983) counsel means "advice given" or "a policy or plan of action or behavior." It is, therefore, not uncommon for some clients to think that genetic counselors will aid them in their decision making. The majority of genetic counselors, however, feel strongly that giving advice to clients about reproductive decisions or other decisions related to genetic disorders as an inappropriate professional role (Sorenson et al. 1981).

Kelley (1986) recommends that at the outset of the session, genetic counselors state the purpose of the session and outline the areas to be covered.

Some researchers argue that sympathetic communication between counselor and counselee is central to good counseling. Genetic counseling, like other health counseling, "does not occur in a hermetically sealed vacuum, where technical knowledge is the major source of good communication, advice, and counsel" (Duster, 1990, p. 82). Genetic disorders vary with racial and ethnic groups and are unevenly distributed through the class structure. Therefore, the social and political context in which the counseling takes place and the amount of information given to the counselee may be as equally important to the counselee as the technical sophistication of the counselor (Duster, 1990; Kessler, 1992a).

#### Effectiveness Of Genetic Counseling

Genetic counseling has been shown to be effective in educating counselees about diagnostic issues, recurrence risks or both (Kessler, 1992a; Seidenfeld and Antley, 1981; Sorenson et al., 1981; Rowley et al., 1984). The criteria most consistently used by genetic counselors to evaluate their work are, most importantly, the level of client medical-genetic knowledge post-counseling and, secondly, client reproductive intentions and/or behavior post-counseling (Sorenson, et al., 1981).

Czeizel et al. (1981) studied the impact of genetic counseling on the family planning decisions of 2,082 families. Two years post-counseling, only 24.7% were able to state correctly the exact figures or specific risks. However, 74.5% knew the order of magnitude of risk; and 91% understood the final advice of the genetic counselor. Of the 88 women who were told that future pregnancies required consideration, 31 had live births; six of these infants had inherited congenital anomalies. Of the 60 women who were told that future pregnancies were not recommended, 23 had live births; 10 of these infants had inherited congenital anomalies. The researchers concluded that the significantly high rate of women of moderate and high risk who chose to follow the counselor's advice to not have more children prove some advantage of the directive approach to counseling in that community.

Sorenson et al. (1981) surveyed 1,097 women who received genetic counseling in 47 clinics located in 25 states and the District of Columbia. Clients were surveyed before counseling, immediately after counseling, and six months post-counseling. A client's diagnostic knowledge was evaluated by asking the individual to name and/or describe the medical problem or disorder for which she had sought genetic counseling. Fifty-eight percent of the female client came to the session with accurate diagnostic knowledge, 18% were marginally accurate; and 20% were inaccurate. There was a 10%

increase in accurate knowledge in the counseled population but 12% remained inaccurate, even though the diagnosis was given in the counseling session. Of the 806 women who responded six months post-counseling, 70% accurately reported the diagnosis, 15% marginally did so, and 10% remained inaccurate.

In evaluating client's knowledge of risk, six percent reported accurate knowledge before counseling and 38% were inaccurate. Immediately after the session 22% reported accurate knowledge, but 21% were still inaccurate. Six months post-counseling, 19% reported accurate knowledge, and 26.8% were inaccurate. In 57% of all cases in the study, it was not possible to assess the accuracy of a client's risk knowledge, even if they reported a figure. This was due to the counselor needing more information, the counselor not reporting to the researchers the risk reported to the clients, and in almost 15% of all cases, the counselor reporting a non-numeric (high, medium, low) risk to the clients.

One of the most important observations made in the study by Sorenson et al. (1981) was that established, experienced counselors had virtually the same proportion of clients leaving counseling ignorant as to their risk and diagnosis, as did younger, inexperienced counselors. The researchers attributed this to the counselor's lack of opportunity, other than a single encounter with the clients, to assess how effective they have been as educators. Davis (1984) recommends using videotapes to provide opportunities to

evaluate and improve interview techniques, as well as to examine different strategies in presenting emotionally laden materials.

Somer et al. (1988) surveyed 791 families who received genetic counseling at public health departments in Finland between 1972 and 1981. Seventy-five percent of those who were counseled during the earliest years (1972-1974) knew the mode of inheritance compared with 83% of the rest of the study population (1975-1988). Of the 101 families who had counseling during a pregnancy, 85% recalled the mode of inheritance and 79% the recurrence risk, compared with 81% and 76%, respectively, in the non-pregnant group. Sixty-two percent of the respondents stated that counseling had a great or moderate impact on their reproductive plans, and within this group, 62% of families had post-counseling pregnancies. Thirty-three percent of the respondents reported that counseling had little or no impact on their family planning; 41% of this group had post-counseling pregnancies.

Zare et al. (1988) found the gender of the counselor a factor in the effectiveness of genetic counseling. Male counselors spent more time than female counselors discussing topics other than the core counseling issues. The researchers stated that lack of discussion of significant issues increases the likelihood that patient reproductive decisions will be based on less information than is available. Female counselors, on the other hand, were reported as being more

sensitive to the specific medical and genetic concerns and questions of their patients. The researchers concluded that the process of medical education, as well as subsequent training, contribute to the acquisition of attitudes that may condition male providers to be more reserved and less involved with women patients than female providers.

CHAPTER 3  
RESEARCH DESIGN AND METHODOLOGY

This study was part of a project conducted under the aegis of the Morehouse School of Medicine in Atlanta, Georgia and the University of Florida College of Medicine in Gainesville, Florida. The project, "The Impact of Human Genome Initiative Derived Technologies on Genetic Testing, Screening and Counseling: Social, Ethical and Legal Issues" was funded by the Department of Energy (DOE) and the National Institutes of Health (NIH). The objectives of the project were to:

1. Analyze and compare/contrast the statutory schemes and services provided by the newborn genetic screening programs in Florida and Georgia with a particular focus on:
  - a. comparing urban/rural population access to the system
  - b. profiling personnel responsible for genetic counseling
  - c. describing the extent and nature of genetic counseling provided by state agencies
  - d. comparing minority population access and use of the system

- e. describing provisions made for service to indigent persons
  - f. describing systems follow-up of those who may reside in the state beyond childhood
2. Identify and analyze legal and ethical issues involving confidentiality of genetic information in comparison to rights, duties and privileges established by statutory and case law and embraced in ethical codes of professional conduct.
  3. Categorize situations likely to create conflicts between index persons and third parties claiming right to know sensitive genetic information.
  4. Categorize and characterize observed rural/urban and ethnic inequalities.

Data for this project were obtained through in-depth interviews with key resource persons at the state and local levels, in-depth interview with genetic counselors at regional genetic centers, site visits to regional genetic centers, and legal research of statutory and case law.

As part of the project, the current study sought to answer the following questions:

1. What are the qualifications and training of professionals in the Southeastern United States who provide genetic counseling?

2. What are the current roles (i.e. functions, duties, and contributions) of nurses, genetic associates, and physicians in the genetic counseling process.
3. What are the perceptions of nurses, genetic associates, and physicians regarding what their roles (i.e. functions, duties, and contributions) should be in the genetic counseling process?
4. What are the educational methods used by these health professionals in genetic counseling?

The study consisted of a mail survey of persons who do genetic counseling in the Southeastern United States (Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee).

#### Survey Research

This phase of the research consisted of questionnaire development, self-administration of the mail survey, quantitative analysis of the data, survey of programs that prepare genetic counselors, and descriptive analyses of these programs. Permission to conduct this study was obtained from the University of Florida's Human Subjects Committee (Appendix 1).

#### Subjects

Subjects were health care providers who provide genetic counseling in the Southeastern United States (Alabama,

Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee) who were members of the Southeast Regional Genetics Group (SERGG), the National Society of Genetic Counselors, and the American Society of Human Genetics. The genetic facilities and centers listed in the SERGG directory were contacted prior to the mailing to verify and update the employment status of persons listed in the directory. Subjects included nurses, master's trained genetic counselors, and physicians. Data from social workers were used for descriptive purposes since social workers represent a small proportion of genetic counselors and there were insufficient numbers for any meaningful statistical analysis.

### Instrument

A self-administered questionnaire was developed based on data from the review of the literature, previous instruments used in other genetic counseling studies, data from the larger project, in-depth interviews of practicing genetic counselors, and curricula information from genetics training programs. The Total Design Method of mail surveys outlined by Dillman (1978) was used to develop and implement the mail survey.

The instrument was reviewed for content validity by a panel of experts. The panel included faculty members from six institutions that train genetic counselors and two master's trained genetic counselors at a university teaching hospital.

Five nurses, five master's trained genetic counselors, and five physicians were sent a pilot copy of the instrument. Nine returned the questionnaires within the requested time frame. Minor revisions were made after the instrument was pilot tested. Subjects used in the pilot test were not used in the final study.

### Procedures

A questionnaires and a self-addressed stamped envelope were mailed to subjects along with a letter describing the study and instructions for returning the questionnaire. A return graph was used to monitor the response rate. A second follow-up was mailed to non-respondents three weeks after the original mailing. It consisted of a questionnaire, a cover letter, and another self-addressed stamped envelope. A third mailing was not sent since a target sample of 200 was achieved.

### Data Analysis

Data gathered through the mail survey were analyzed using the Statistical Analysis System (SAS) on a mainframe computer. Descriptive statistics were employed. Analysis of Variance (ANOVA) were used to test differences between groups. Appropriate post-hoc tests were conducted as needed. For pairwise comparisons, the familywise error rate was

controlled, and the Studentized Maximum Modulus was used. Statistical significance was assessed at .05. Chi square was used to determine differences among frequencies and proportions in different categories.

CHAPTER 4  
RESULTS

Descriptive Findings

Response Rate

Questionnaires were sent to 325 identified health professionals who provided genetic counseling in the Southeastern United States. Two hundred twenty (63%) were returned. Of the 220 returned, 204 volunteered for the study; 6 were retired and refused to participate; 4 refused because they did not counsel clients and ruled themselves ineligible for the study; and 6 returned the unanswered survey without any explanations. The response rate was calculated by the following formula, which excluded

unmade contacts from consideration (Dillman, 1978).

$$\text{Response rate} = \frac{\text{number returned}}{(\text{sample size} - (\text{noneligible} + \text{nonreachable}))} \times 100$$

$$\text{Response rate} = \frac{220}{(325 - (6 + 4 + 6))} \times 100$$

$$\text{Response rate} = 71.2\%$$

Demographics

Ninety-one percent of the respondents (n = 170) described themselves as White, five percent (n = 9) as Black, three

percent (n = 5) as Hispanic, two percent (n = 3) as Asian, and one percent (n = 1) as other. Seventy percent were females (n = 132) and 30% (n = 57) were males. See Table 4-1.

Table 4-1 Respondents by race and gender (n = 189).

Race	Female		Male	
	n	%	n	%
White	119	90	52	91
Black	8	6	1	2
Hispanic	3	2	2	4
Asian	1	1	2	4
Other	1	1	0	0

Note: percentage may not add up to 100 due to rounding.

### Education

Thirty percent (n = 57) were physicians; 32% (n = 60) were certified genetics associates; 23% (n = 43) were nurses; 3% (n = 7) were social workers. Non-physicians with PhDs had doctoral degrees in such fields as molecular biology, genetics, education, and psychology (Table 4-2).

### Genetic Counseling Team

Genetic counseling is usually done by physicians and genetic associates (26%); and by physicians, nurses, and genetic associates (16%). Table 4-4 shows the various members of the genetic counseling teams and Table 4-5 shows the current job titles/positions.

Table 4-2 Educational status (n = 198).

Professional	no.	%
Physicians	47	24
Physicians (MD,PhD)	9	5
Physicians (MD,MS)	1	1
Nurses (MSN)	8	4
Nurses (BSN)	35	18
Genetic associates (MS)	55	29
Genetic associates (MS,PhD)	5	3
Social Workers (MSW/MSSW)	7	3
Other PhD	18	10
Other master's	7	4
Other bachelor's	4	2
Associate degree	2	1

Note: percentages may not add up to 100 due to rounding

Table 4-3 Length of time doing genetic counseling.

Professional	Overall	Present Facility
Physicians	13 ± 9.7	9 ± 9.4
Nurses	6 ± 4.4	6 ± 4.4
Genetic assoc. (PhD)	13 ± 8.4	9 ± 5.4
Genetic assoc. (MS)	6 ± 4.5	4 ± 2.3
Social workers	10 ± 3.9	9 ± 3.7
Other PhD	12 ± 8.0	12 ± 7.4

Table 4-4 Members of the genetic counseling team (n = 201).

Team member	no.	%
MD	7	4
RN	11	6
GC	11	6
SW	1	1
Other	7	4
MD and RN	15	8
MD and GC	52	26
MD, RN, GC	32	16
MD, RN, GC, SW	1	1
RN and GC	6	3
GC and Intern	2	1
MD, RN, GC, Intern	5	3
MD, RN, Other	2	1
MD, NP, GC, Other	1	1
MD and NP	7	4
GC, SW, Intern	1	1
MD and Other	1	1
MD and SW	3	2
MD, GC, Intern	9	5
MD, NP, GC	7	4
MD, GC, Other	7	4
RN, GC, SW	1	1
MD, GC, SW	4	2
MD and SW	2	1
MD, NP, RN, GC, Intern	2	1
MD, NP, RN, GC	3	2
MD, RN, SW	1	1

Note: percentages may not add up to 100% due to rounding.

MD = physician; RN = registered nurse; GC = genetic associate; SW = social worker; NP = nurse practitioner; Intern = graduate student in genetic counseling; Other = lab director or other health professional.

Table 4-5 Current job title/position (n = 199).

Job title/position	no.	%
Genetic counselor	50	25
Clinical/medical geneticist	33	17
Clinical nurse specialist	17	9
Social worker/family therapist	4	2
Administrator/clinic coordinator	18	9
Clinical instructor/faculty	8	4
Other	18	9
Genetic counselor and administrator	5	3
Genetic counselor, admin., faculty	6	3
Clinical/medical geneticist and admin.	2	1
Clinical/medical geneticist, faculty	15	8
Clinical/medical geneticist, admin., faculty	3	2
Clinical nurse specialist and administrator	2	1
Genetic counselor and faculty	15	8
Social worker/family therapist and faculty	1	1

#### Prevalence of Genetic Disorders Among Respondents

The majority of respondents (55%, n = 102) reported neither they, their family members, nor their close friends had a genetic disorder (Table 4-6).

The majority of respondents (62%, n = 111) were not involved with any genetic support group. Eighty-three percent of those involved with support groups (n = 57) did not think only genetic associates should do genetic counseling. The majority (62%, n = 23) of those who had personal encounters with a genetic disorder (themselves, friend, and/or family member) did not believe only genetic associates should do genetic counseling.

Table 4-6 Prevalence of genetic disorders among respondents (n = 187).

Person	no.	%
Neither I, family, nor friend	102	55
Self	4	2
Family member	32	17
Friend	26	14
Self and family member	2	1
Self and friend	5	3
Self, family, friend	7	4
Family member and friend	9	5

### Facility

The majority of the respondents (61%, n = 123) worked at university medical centers. Nurses with bachelor's degrees were more likely to work at public health departments (Table 4-7). Seventy-two percent of the facilities were located in urban areas; 16% in rural areas; and 12% in suburban areas.

Forty-eight percent (n = 95) of the facilities had 3 certified genetic counselors; 24% percent of the facilities (n = 48) had only 1; 12% (n = 23) had 2; 8% (n = 15) had 4; 4% (n = 7) had 5; 4% (n = 8) had 6; and 2% (n = 4) had 7.

### Patient Population

Forty-five percent of respondents (n = 91) described their patient population as a mixture of pediatric and prenatal clients; 20 % (n = 42) as prenatal; 18% (n = 37) as general public; 12% (n = 25) as pediatric; and 4% (n = 7) as other (Table 4-8).

Table 4-7 Facilities where the respondents work (n = 202).

Facility	MD		GC		RN		SW	
	no.	%	no.	%	no.	%	no.	%
University medical center	44	79	41	76	13	33	5	83
Public hospital	1	2	3	6	1	3	0	0
Public health department	0	0	1	2	22	56	0	0
Private/group practice	4	7	2	4	2	5	0	0
Commercial genetics lab	3	5	4	7	2	5	0	0
Other	5	9	3	6	0	0	0	0

Note percentage may not add up to 100 due to rounding.

MD = all physicians; GC = all genetic associates; RN = all nurses; SW = social workers.

Table 4-8 Patient population (n = 167).

Population	MD		GC		RN		SW	
	no.	%	no.	%	no.	%	no.	%
Pediatric	14	25	4	7	14	23	1	15
Prenatal	8	14	22	37	1	2	0	0
Pediatric and prenatal	25	45	27	49	22	51	4	57
General pop.	7	13	4	7	4	2	2	29
Other	3	5	1	2	4	9	0	0

Note percentage may not add up to 100 due to rounding.

MD = all physicians; GC = all genetic associates; RN = all nurses; SW = social workers.

Professional Preparation: Human Genetics

When asked to describe their training in human genetics, 53% (n = 107) respondents reported they had college course work in human genetics, supervised clinical training, and seminar/workshop training. Thirteen percent (n = 26) only had seminar/workshop training; 7% (n = 14) had supervised clinical training and had seminar/workshop training; 6% (n = 12) had other training, but did not specify; 5% (n = 10) only had supervised clinical training; 5% (n = 11) had college course work in human genetics, supervised clinical training, seminar/workshop training, and clinical fellowships; 3% (n = 5) had college course work in human genetics and supervised clinical training; 2% (n = 3) had no training whatsoever (Table 4-9).

Table 4-9 Training in human genetics (n = 158).

Training	MD		GC		RN		SW	
	no.	%	no.	%	no.	%	no.	%
Course work, clinical training and seminar/workshop	25	45	55	93	13	36	3	43
Course work, clinical training, seminar/workshop, fellowship	6	11	0	0	0	0	0	0
Course work and clinical training	2	4	1	2	0	0	0	0
Course work and seminar/workshop	0	0	2	3	0	0	1	14

Table 4-9--continued

Training	MD		GC		RN		SW	
	no.	%	no.	%	no.	%	no.	%
Clinical training & seminar/workshop	4	7	1	2	4	11	1	14
Course work	1	2	0	0	0	0	0	0
Clinical training	5	9	0	0	2	6	0	0
Seminar/workshop	3	5	1	2	15	42	2	29
Other training	9	16	0	0	0	0	0	0
No training whatsoever	0	0	0	0	2	6	0	0

Note percentage may not add up to 100 due to rounding.  
 MD = all physicians; GC = all genetic associates; RN = all nurses; SW = social workers.

The majority of other health professionals with PhDs (56%, n = 9) had college course work in human genetics, supervised clinical training, and seminar/workshop training.

#### Professional Preparation: Counseling Techniques

Thirty percent of respondents (n = 59) had college course work in counseling techniques, supervised clinical training, and seminar/workshop training. Twenty percent (n = 38) had supervised clinical training and seminar/workshop training; 15% (n = 29) had only supervised clinical training; 11% (n = 21) had only seminar/workshop training; 8% (n = 15) had college course work and supervised clinical training; 6% (n = 12) had no training whatsoever; 5% (n = 9) had only college

course work; 2% (n = 3) had college course work in counseling techniques, supervised clinical training, and seminar/workshop training, and clinical fellowships.

Table 4-10 Training in counseling techniques (n = 147).

Training	MD		GC		RN		SW	
	no.	%	no.	%	no.	%	no.	%
Course work, clinical training and seminar/workshop	9	16	37	55	7	21	7	100
Course work, clinical training, seminar/workshop, fellowship	0	0	0	0	0	0	0	0
Course work and clinical training	2	4	0	0	1	3	0	0
Course work and seminar/workshop	0	0	13	22	4	12	0	0
Clinical training & seminar/workshop	14	25	6	10	1	3	0	0
Course work	3	5	4	7	1	3	0	0
Clinical training	15	27	3	5	5	15	0	0
Seminar/workshop	7	13	0	0	9	27	0	0
Other training	0	0	0	0	0	0	0	0
No training whatsoever	7	13	0	0	5	15	0	0

Note percentage may not add up to 100 due to rounding.

MD = all physicians; GC = all genetic associates; RN = all nurses; SW = social workers.

Nineteen percent of other health professionals with PhDs (n = 3) had college course work in counseling techniques, supervised clinical training, and seminar/workshop training; 25% (n = 3) had only supervised clinical training; 25% (n = 3)



Table 4-11--continued

Training	MD		GC		RN		SW	
	no.	%	no.	%	no.	%	no.	%
Course work and clinical training	0	0	3	5	0	0	0	0
Course work and seminar/workshop	0	0	3	5	4	12	1	14
Clinical training & seminar/workshop	6	11	6	10	1	3	3	43
Course work	2	4	7	12	4	11	1	14
Clinical training	3	9	1	2	0	0	0	0
Seminar/workshop	11	19	9	16	12	32	0	0
Other training	2	4	1	2	2	5	0	0
No training whatsoever	24	42	17	29	5	13	1	14

Note percentage may not add up to 100 due to rounding.

MD = all physicians; GC = all genetic associates; RN = all nurses; SW = social workers.

Forty-four percent of other health professionals with PhDs ( $n = 8$ ) had no training whatsoever in educational methods and principles; 22% ( $n = 4$ ) had only seminar/workshop training; 17% ( $n = 3$ ) had only supervised clinical training; 11% ( $n = 2$ ) had college course work in educational methods and principles, supervised clinical training, and attended seminars/workshops.

#### Inferential Statistics

Only responses for physicians, genetic counselors, and nurses are analyzed. Contingency tables and  $\chi^2$  tests were used for bivariate analyses. Because of the small numbers of

social workers in the study, many responses related to social workers had cells with expected counts less than five;  $\chi^2$  values may not be valid and these values are not reported. However, the percentages are given for information purposes. Analysis of variance (ANOVA) was used to analyze differences between groups. Welch's  $t$  was used to analyze differences between two groups assumed to have unequal variances. Dunnet's  $T_3$  was used to make pairwise comparisons between groups assumed to have unequal variances. For pairwise comparisons, the familywise error rate was controlled, and the Studentized Maximum Modulus was used to determine critical values.

#### Work Week

Contingency tables and  $\chi^2$  tests were used for bivariate analyses.

The number of hours spent on genetic counseling depended on the health professional [ $(\chi^2 (2), n = 150) = 32.069, P = 0.000$ ] (Table 4-12). Thirty-six percent of physicians spent 5 to 10 hours/week; 28% spent less than 5 hours/week; and 23% spent 11-15 hours/week. Thirty-three percent of genetic counselors spent 11 to 15 hours/week and 28% spent more than 20 hours/week. Forty percent of nurses spent less than 5 hours/week.

The number of hours spent on clerical/administrative tasks depended on the health professional [ $(\chi^2 (2), n = 150)$

= 26.39,  $P = 0.001$ ] (Table 4-14). Forty-five percent of physicians spent 5 to 10 hours/week. Thirty-one percent of genetic counselors spent 11-15 hours/week and 28% spent 5 to 10 hours/week. Thirty-two percent of nurses spent less than 5 hours/week and 24% spent more than 20 hours/week.

The length of the average genetic counseling session depended on the health professional [ $\chi^2$  (2),  $n = 150$ ) = 11.95,  $P = 0.018$ ] (Table 4-16). The majority of physicians (69%), genetic counselors (79), and nurses (53%) spent 30 to 60 minutes.

The majority of physicians (63%) saw one to nine patients/week for genetic counseling; 38% saw ten to 20 patients/week. The majority of genetic counselors (54%) saw ten to 20 patients/week; 40% saw one to nine patients/week. The majority of nurses (51%) saw one to nine patients/week; 30% saw 10 to 20 patients/week and 19% saw none (Table 4-18).

The majority of physicians, genetic associates, and nurses spent less than 5 hours/week on genetic-related educational activities (Table 4-21).

Table 4-12. Hours spent on genetic counseling:  $\chi^2$  analysis.

Hours/week	no.	%
<b>Less than 5</b>		
Physicians	15	27
Genetic associates	4	7
Nurses	15	41
<b>5 to 10</b>		
Physicians	20	36
Genetic associates	9	16
Nurses	8	22
<b>11 to 15</b>		
Physicians	13	23
Genetic associates	19	33
Nurses	5	14
<b>16 to 20</b>		
Physicians	4	7
Genetic associates	9	16
Nurses	6	16
<b>More than 20</b>		
Physicians	4	7
Genetic associates	16	28
Nurses	3	8

$\chi^2$  ((2) n = 160) = 32.069, P = 0.000

Table 4-13. Hours spent doing genetic counseling (n = 183).

Hours/week	MD		MD&PhD		GC		PhD&GC	
	no.	%	no.	%	no.	%	no.	%
Less than 5	13	28	2	22	1	2	3	60
5 to 10	17	37	3	33	9	17	0	0
11 to 15	11	24	2	22	18	35	1	20
16 to 20	3	7	1	1	9	17	0	0
More than 20	2	4	1	1	15	29	1	20

Table 4-13--continued

Hours/week	PhD		MSN		BSN		MSSW	
	no	%	no	%	no	%	no	%
Less than 5	10	71	0	0	15	50	1	20
5 to 10	4	29	5	71	3	10	1	20
11 to 15	0	0	1	14	4	13	2	40
16 to 20	0	0	1	14	5	17	1	20
More than 20	0	0	0	0	3	10	0	0

Note: percentages may not add up to 100 due to rounding

PhD = health professionals with other doctoral degree;

MSN = master's in nursing; BSN = bachelor's in nursing; and

MSSW = master's in social work.

Table 4-14. Hours spent on clerical/administrative tasks:  $\chi^2$  analysis.

Hours/week	no.	%
<b>Less than 5</b>		
Physicians	5	9
Genetic associates	3	5
Nurses	12	32
<b>5 to 10</b>		
Physicians	25	45
Genetic associates	16	28
Nurses	7	18
<b>11 to 15</b>		
Physicians	10	18
Genetic associates	18	31
Nurses	3	8
<b>16 to 20</b>		
Physicians	7	10
Genetic associates	10	17
Nurses	7	18
<b>More than 20</b>		
Physicians	9	16
Genetic associates	11	19
Nurses	9	24

$\chi^2$  (2)  $n = 152 = 23.39$ ,  $P = 0.001$

Table 4-15. Hours spent on clerical/administrative duties (n = 188).

Hours/week	MD		MD, PhD		GC		PhD, GC	
	no	%	no	%	no	%	no	%
Less than 5	4	9	1	11	2	4	1	20
5 to 10	22	48	2	22	14	26	2	40
11 to 15	9	20	1	11	18	34	0	0
16 to 20	4	9	3	33	8	17	2	40
More than 20	7	15	1	6	11	21	0	0

**Note:** percentages may not add up to 100 due to rounding  
 MD = physician; MD, PhD = physicians with doctoral degree;  
 GC = master's trained genetic counselors/associates;  
 PhD, GC = genetic associates with doctoral degrees.

Table 4-15--continued

<u>Hours/week</u>	PhD		MSN		BSN		MSSW	
	no	%	no	%	no	%	no	%
Less than 5	4	25	2	29	10	32	2	23
5 to 10	6	38	3	43	4	13	1	17
11 to 15	2	13	0	0	3	10	1	17
16 to 20	3	19	0	0	7	23	2	33
More than 20	1	6	2	29	7	23	0	0

Note: percentages may not add up to 100 due to rounding

PhD = health professionals with other doctoral degree;

MSN = master's in nursing; BSN = bachelor's in nursing; and

MSSW = master's in social work.

Table 4-16. Average length of genetic counseling session in minutes:  $\chi^2$  analysis.

Minutes	MD		GC		RN	
	no.	%	no.	%	no.	%
Less than 30	7	13	3	6	11	29
30 to 60	38	69	46	79	20	53
More than 60	10	18	9	16	7	18

$\chi^2 (2), n = 151 = 11.95, P = 0.018$

Table 4-17. Average length of genetic counseling session in minutes (n = 183).

Minutes	MD		MD, PhD		GC		PhD, GC	
	no	%	no	%	no	%	no	%
Less than 30	6	13	1	11	2	4	1	20
30 to 60	29	64	8	89	44	83	2	40
More than 60	10	22	0	0	7	13	2	40

Note: percentages may not add up to 100 due to rounding  
 MD = physician; MD/PhD = physicians with PhD; GC = master's trained genetic associates; PhD, GC = genetic associates with doctoral degrees.

Table 4-17--continued

Minutes	PhD		MSN		BSN		MSSW	
	no	%	no	%	no	%	no	%
Less than 30	0	0	0	0	11	35	0	0
30 to 60	7	54	4	57	16	52	3	50
More than 60	6	46	3	43	4	13	3	50

Note: percentages may not add up to 100 due to rounding  
 PhD = health professionals with other doctoral degree;  
 MSN = master's in nursing; BSN = bachelor's in nursing; and  
 MSSW = master's in social work.

Table 4-19. Number of patients seen by health professional  
(n = 150).

Number of Patients	no.	%
Zero		
Physicians	0	0
Genetic associates	1	2
Nurses	7	19
1 to 9		
Physicians	35	63
Genetic associates	23	40
Nurses	19	51
10 to 20		
Physicians	21	38
Genetic associates	31	28
Nurses	11	30
21 to 30		
Physicians	0	0
Genetic associates	1	2
Nurses	0	0
More than 30		
Physicians	0	0
Genetic associates	1	2
Nurses	0	0

Table 4-20. Number of patients per week seen by health professionals (n = 186).

Patients	MD		MD, PhD		GC		PhD, GC	
	no	%	no	%	no	%	no	%
Zero	0	0	0	0	1	2	0	0
1 to 9	31	67	4	44	14	26	3	60
10 to 20	15	33	5	56	18	34	2	40
21 to 30	0	0	0	0	8	17	0	0
More than 30	0	0	0	0	11	21	0	0

Note: percentages may not add up to 100 due to rounding  
 MD = physician; MD, PhD = physicians with doctoral degree;  
 GC = master's trained genetic counselors/associates;  
 PhD, GC = genetic associates with doctoral degrees.

Table 4-20--continued

Patients	PhD		MSN		BSN		MSSW	
	no	%	no	%	no	%	no	%
Less than 5	5	31	0	0	7	23	1	14
5 to 10	11	69	6	86	13	43	4	57
11 to 15	0	0	1	14	10	33	2	29
16 to 20	0	0	0	0	0	0	0	0
More than 20	0	0	0	0	0	0	0	0

Note: percentages may not add up to 100 due to rounding  
 PhD = health professionals with other doctoral degree;  
 MSN = master's in nursing; BSN = bachelor's in nursing; and  
 MSSW = master's in social work.

Table 4-21. Hours per week spent on genetic-related educational activities (n = 189).

Hours/week	MD		MD, PhD		GC		PhD, GC	
	no	%	no	%	no	%	no	%
Zero	13	28	2	22	14	26	2	40
Less than 5	29	63	5	56	34	64	2	40
5 to 10	41	9	1	11	4	8	0	0
More than 10	0	0	1	11	1	2	1	20

Note: percentages may not add up to 100 due to rounding  
 MD = physician; MD, PhD = physicians with doctoral degree;  
 GC = master's trained genetic counselors/associates;  
 PhD, GC = genetic associates with doctoral degrees.

Table 4-21--continued

Hours/week	PhD		MSN		BSN		MSSW	
	no	%	no	%	no	%	no	%
Zero	2	13	0	0	11	34	2	29
Less than 5	7	44	6	86	20	63	5	71
5 to 10	5	31	1	14	1	3	0	0
More than 10	2	13	0	0	0	0	0	0

Note: percentages may not add up to 100 due to rounding  
 PhD = health professionals with other doctoral degree;  
 MSN = master's in nursing; BSN = bachelor's in nursing; and  
 MSSW = master's in social work.

### Counseling Goals

Respondents were asked to rate the importance of six counseling goals on a four-point Likert scale. On the scale, very important = 4, important = 3, somewhat important = 2, and not important = 1. Analysis of variance was used to analyze differences between groups (Table 4-28), and Dunnett's T3 was used for post-hoc comparisons (Table 4-29).

Fifty-eight percent ( $n = 111$ ) of all respondents thought it was very important or important that their counseling prevent disease or abnormality. There was a significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,151) = 18.31$ ,  $P = 0.0001$ ]. Physicians and nurses were more likely than genetic counselors to indicate that it was important that their counseling prevent disease or abnormality. There was no significant difference between physicians and nurses.

The majority (58%,  $n = 107$ ) did not think it was important that their counseling reduce the number of carriers of genetic disorders in the population. There was a significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,149) = 27.26$ ,  $P = 0.0001$ ]. Physicians were as likely as genetic counselors to indicate that it was not important that their counseling reduce the number of carriers. Physicians and genetic counselors were more likely than nurses to indicate

that it was not important that their counseling reduce the number of carriers.

Sixty-three percent ( $n = 121$ ) thought it was important or very important that their counseling improve the general health of the population. There was a significant difference in response among physicians, genetic counselors, and nurses with respect to this variable; [ $F(2,151) = 18.12, P = 0.0001$ ]. Nurses were more likely than physicians, and physicians were more likely than genetic counselors, to say it was important that their counseling improve the general health of the population.

Ninety-two percent ( $n = 179$ ) thought it was important or very important that their counseling should help families adjust to and cope with their genetic disorders. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,151) = 1.58, P = 0.2102$ ].

Ninety-nine percent ( $n = 191$ ) thought that it was important or very important that their counseling remove or lessen the patient's guilt or anxiety. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,151) = 0.76, P = 0.4673$ ].

Ninety percent ( $n = 174$ ) thought it was important or very important that their counseling help couples achieve their parenting goals. There was a significant difference in

response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,151) = 4.44, P = 0.0133$ ]. Physicians were more likely than genetic counselors to say it was important that their counseling help individual couples achieve their parenting goals. There was no significant difference in response between physicians and nurses and genetic counselors and nurses.

Table 4-22. Prevent disease or abnormality (n = 177).

Professional	VI		I		SI		NI	
	no.	%	no.	%	no.	%	no.	%
Physicians	17	31	18	33	15	27	6	11
Genetic associates	7	12	12	20	28	47	14	23
Nurses	22	56	9	23	5	13	3	8
Social workers	3	50	2	33	0	0	1	17
Other PhD	6	40	3	29	3	20	3	20

Note: percentages may not add up to 100 due to rounding;  
 Physicians = all physicians; Nurses = all nurses; Genetic associates include PhDs  
 VI = very important; I = important; SI = somewhat important;  
 NI = not important;

Table 4-23. Reduce the number of carriers (n = 173).

Professional	VI		I		SI		NI	
	no.	%	no.	%	no.	%	no.	%
Physicians	5	9	7	13	6	11	38	68
Genetic associates	0	0	5	9	11	19	42	72
Nurses	14	37	9	24	7	18	8	21
Social workers	3	50	1	17	0	0	2	33
Other PhD	0	0	3	20	2	13	10	67

Note: percentages may not add up to 100 due to rounding;  
 Physicians = include physicians with PhD and MS degrees;  
 Genetic associates = include those with PhD;  
 Nurses = include those with MS  
 VI = very important; I = important; SI = somewhat important;  
 NI = not important;

Table 4-24. Improve the health of the population (n = 173).

Professional	VI		I		SI		NI	
	no.	%	no.	%	no.	%	no.	%
Physicians	24	44	13	24	10	18	8	15
Genetic associates	11	19	10	17	29	50	8	14
Nurses	26	67	10	26	3	8	0	0
Social workers	2	33	3	50	1	17	0	0
Other PhD	7	47	3	20	2	13	3	20

Note: percentages may not add up to 100 due to rounding;  
 Physicians = include physicians with PhD and MS degrees;  
 Genetic associates = include those with PhD;  
 Nurses = include those with MS  
 VI = very important; I = important; SI = somewhat important;  
 NI = not important;

Table 4-25. Help families adjust to and cope with their genetic disorder (n = 175).

Professional	VI		I		SI		NI	
	no.	%	no.	%	no.	%	no.	%
Physicians	52	93	4	7	0	0	0	0
Genetic associates	57	97	2	3	0	0	0	0
Nurses	34	87	5	13	0	0	0	0
Social workers	6	100	0	0	0	0	0	0
Other PhD	14	97	1	7	0	0	0	0

Note: percentages may not add up to 100 due to rounding;  
 Physicians = include physicians with PhD and MS degrees;  
 Genetic associates = include those with PhD;  
 Nurses = include those with MS  
 VI = very important; I = important; SI = somewhat important;  
 NI = not important;

Table 4-26. Remove or lessen the patient's guilt or anxiety (n = 175).

Professional	VI		I		SI		NI	
	no.	%	no.	%	no.	%	no.	%
Physicians	47	84	8	14	1	2	0	0
Genetic associates	51	86	7	12	0	0	1	2
Nurses	36	92	3	8	0	0	0	0
Social workers	5	83	1	17	0	0	0	0
Other PhD	12	80	2	13	1	7	0	0

Note: percentages may not add up to 100 due to rounding;  
 Physicians = include physicians with PhD and MS degrees;  
 Genetic associates = include those with PhD;  
 Nurses = include those with MS  
 VI = very important; I = important; SI = somewhat important;  
 NI = not important;

Table 4-27. Help individual couples achieve their parenting goals (n = 174).

Professional	VI		I		SI		NI	
	no.	%	no.	%	no.	%	no.	%
Physicians	48	86	6	11	1	2	1	2
Genetic associates	34	58	18	31	5	9	1	2
Nurses	25	64	10	26	3	8	1	3
Social workers	4	67	2	33	0	0	0	0
Other PhD	9	60	1	7	4	27	1	7

Note: percentages may not add up to 100 due to rounding;  
 Physicians = include physicians with PhD and MS degrees;  
 Genetic associates = include those with PhD;  
 Nurses = include those with MS  
 VI = very important; I = important; SI = somewhat important;  
 NI = not important;

Table 4-28. Omnibus tests of counseling goals.

Goal	F-statistic	P
Prevent disease or abnormality	[F (2,151) = 18.31]	0.0001*
Reduce the number of carriers	[F (2,149) = 27.26]	0.0001*
Improve the health of the population	[F (2,151) = 18.12]	0.0001*
Help families adjust/cope with disorder	[F (2,151) = 1.58]	0.2102
Remove or lessen the patient's guilt/anxiety	[F (2,151) = 0.76]	0.4673
Help couples achieve their counseling goals	[F (2,151) = 4.44]	0.0133*

\* significant

Table 4-29. Post-hoc comparisons of significant results by health professionals

Goal	no.	mean	t-statistic	critical value	P
<b>Prevent disease or abnormality</b>					
Physicians	56	2.82 ± 0.99			
Genetic counselors	59	2.13 ± 0.88	[ $\bar{t}$ (110) = 3.91]	[ $\pm V_{.05,110}$ = 2.39]	P < .05*
Nurses	39	3.23 ± 0.97			
Genetic counselors	59	2.13 ± 0.88	[ $\bar{t}$ (78) = - 5.93]	[ $\pm V_{.05,78}$ = 2.39]	P < .05*
Physicians	56	2.82 ± 0.99			
Nurses	39	3.23 ± 0.97	[ $\bar{t}$ (83) = - 2.25]	[ $\pm V_{.05,83}$ = 2.39]	P > .05
<b>Reduce the number of carriers</b>					
Physicians	56	1.62 ± 1.01			
Genetic counselors	58	1.36 ± 0.64	[ $\bar{t}$ (92) = 1.64]	[ $\pm V_{.05,92}$ = 2.39]	P > .05
Nurses	38	2.76 ± 1.17			
Genetic counselors	58	1.36 ± 0.64	[ $\bar{t}$ (52) = -6.73]	[ $\pm V_{.05,52}$ = 2.47]	P < .05*
Physicians	56	1.62 ± 1.01			
Nurses	38	2.76 ± 1.17	[ $\bar{t}$ (72) = -4.86]	[ $\pm V_{.05,72}$ = 2.39]	P < .05*
<b>Improve the health of the population</b>					
Physicians	55	2.96 ± 1.10			
Genetic counselors	58	2.41 ± 0.95	[ $\bar{t}$ (107) = 2.82]	[ $\pm V_{.05,107}$ = 2.39]	P < .05*

Table 4-29--continued

Goal	no.	mean	t-statistic	critical value	P
<b>Improve the health of the population</b>					
Nurses	39	3.58 ± 0.63			
Genetic counselors	58	2.41 ± 0.95	[ $\bar{t}$ (95) = -7.26]	[ $\pm V_{.05,3,95}$ = 2.39]	P < .05*
Physicians	55	2.96 ± 1.10			
Nurses	39	3.58 ± 0.95	[ $\bar{t}$ (89) = -3.45]	[ $\pm V_{.05,3,89}$ = 2.39]	P < .05*
<b>Help couples achieve their counseling goals</b>					
Physicians	56	3.80 ± 0.55			
Genetic counselors	59	3.40 ± 0.79	[ $\bar{t}$ (104) = 2.99]	[ $\pm V_{.05,3,104}$ = 2.39]	P < .05*
Nurses	39	3.51 ± 0.75			
Genetic counselors	59	3.40 ± 0.79	[ $\bar{t}$ (84) = -0.56]	[ $\pm V_{.05,3,84}$ = 2.39]	P > .05
Physicians	56	3.80 ± 0.55			
Nurses	39	3.51 ± 0.75	[ $\bar{t}$ (65) = 26.04]	[ $\pm V_{.05,3,65}$ = 2.45]	P > .05

\* significant

### Educational Methods and Principles

Respondents were asked to rate the frequency with which they used 13 educational methods and principles on a four-point Likert scale. On the scale, always = 4, sometimes = 3, rarely = 2, and never = 1. Analysis of variance was used to analyze differences between groups (Table 4-41), and Dunnett's T3 was used for post-hoc comparisons (Table 4-42).

Fifty-eight percent of the respondents (n = 107) reported they always ask patients about their expectations of the counseling session; 34% (n = 65) asked sometimes. There was no significant difference in response among physicians, genetic, counselors and nurses with respect to this variable [ $F(2,150) = 0.66, P = 0.52$ ].

Twenty-nine percent (n = 55) reported they always assess the patient's cultural beliefs; 51% (n = 98) assessed it sometimes. There was no significant differences in response among physicians, genetic, counselors and nurses with respect to this variable [ $F(2,150) = 0.21, P = 0.80$ ].

Seventy-five percent (n = 145) reported they always assess the patient's educational level. There was no significant differences in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 0.83, P = 0.43$ ].

Seventy percent (n = 131) reported they always assess whether the patient is emotionally ready for the information. There was no significant difference in response among

physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 3.03, P = 0.051$ ].

Seventy-six percent ( $n = 145$ ) reported they always prepare the patient for the possibility of uncertain or shocking information. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 2.57, P = 0.07$ ].

Seventy-five percent ( $n = 144$ ) reported they always do individual counseling. There was a significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 11.35, P = 0.0001$ ]. Physicians were as likely as genetic counselors, and more likely than nurses to do individual counseling.

Group counseling was never (54%,  $n = 105$ ) or rarely (27%,  $n = 52$ ) done. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 1.83, P = 0.16$ ].

Pre-tests and post-tests were never (64%,  $n = 121$ ) or rarely (21%,  $n = 39$ ) used to assess the patient's understanding of the facts. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 0.18, P = 0.83$ ].

The readability level of the written materials given to patients were always (37%,  $n = 69$ ) or sometimes (43%,  $n = 80$ ) assessed. There was no significant difference in response

among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 0.26, P = 0.76$ ].

Pamphlets and/or handouts were always (35%,  $n = 66$ ) or sometimes (59%,  $n = 110$ ) given to patients. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 2.95, P = 0.055$ ].

Videos were used sometimes by about one-third of these professionals (35%,  $n = 66$ ); they were more likely to be never (32%,  $n = 60$ ) or rarely (27%,  $n = 48$ ) used. There was no significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 0.78, P = 0.462$ ].

The patient was always (19%,  $n = 36$ ) or sometimes (57%,  $n = 106$ ) asked to repeat what was said in his/her own words. There was a significant difference in response among physicians, genetic counselors, and nurses with respect to this variable [ $F(2,150) = 3.19, P = 0.044$ ]. Nurses were as likely as physicians, but more likely than genetic counselors to ask the patient to repeat what was said in his/her own words.

The need to see a social worker/mental health worker was always ( $n = 38\%$ ,  $n = 73$ ) or sometimes ( $n = 44\%$ ,  $n = 84$ ) assessed. There was no significant differences in response among physicians, genetic, counselors and nurses with respect to this variable [ $F(2,150) = 2.37, P = 0.09$ ].

Table 4-30. Ask the patient about his/her expectations  
(n = 176).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	31	55	21	38	4	7	0	0
Genetic associates	30	51	22	37	7	12	0	0
Nurses	26	68	9	24	1	3	2	5
Social workers	5	71	0	0	1	14	1	14
Other PhD	1	6	2	13	4	25	9	56

Note: percentages may not add up to 100 due to rounding;  
Physicians = all physicians; Genetic associates = all genetic  
associates; Nurses = all nurses.

Table 4-31. Assess the patient's cultural beliefs (n = 195).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	17	30	46	17	13	23	0	0
Genetic associates	12	20	37	63	10	17	0	0
Nurses	14	37	17	45	5	13	2	12
Social workers	5	83	1	17	0	0	0	0
Other PhD	5	31	7	44	2	13	2	13

Note: percentages may not add up to 100 due to rounding;  
Physicians = all physicians; Genetic associates = all genetic  
associates; Nurses = all nurses MS.

Table 4-32. Assess the patient's educational level (n = 177).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	39	70	17	30	0	0	0	0
Genetic associates	51	86	6	10	1	2	1	2
Nurses	29	76	9	24	0	0	0	0
Social workers	4	67	2	33	0	0	0	0
Other PhD	12	75	3	19	0	0	1	2

Note: percentages may not add up to 100 due to rounding;  
Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-33. Assess the patient's emotional readiness (n = 172).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	43	80	10	19	1	2	0	0
Genetic associates	39	67	17	29	2	3	0	0
Nurses	23	61	11	29	3	8	1	3
Social workers	5	83	1	17	0	0	0	0
Other PhD	11	69	3	19	0	0	2	13

Note: percentages may not add up to 100 due to rounding;  
Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-34. Prepare the patient for the possibility of uncertain or shocking information (n = 174).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	48	86	8	14	0	0	0	0
Genetic associates	45	76	12	20	2	3	0	0
Nurses	26	70	9	24	0	0	2	5
Social workers	4	67	2	33	0	0	0	0
Other PhD	12	75	2	13	1	6	1	6

Note: percentages may not add up to 100 due to rounding;  
 Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-35. Do individual counseling (n = 174).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	43	77	11	20	1	2	1	2
Genetic associates	50	86	8	14	0	0	0	0
Nurses	19	50	13	34				

Note: percentages may not add up to 100 due to rounding;  
 Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-36. Assess the readability level of written materials (n = 172).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	24	43	20	36	4	7	8	14
Genetic associates	17	30	30	53	6	11	4	7
Nurses	16	43	15	41	3	8	3	8
Social workers	1	17	4	67	1	17	0	0
Other PhD	7	44	5	31	3	19	1	6

Note: percentages may not add up to 100 due to rounding;  
 Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-37. Use pamphlets and/or handouts (n = 191).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	13	23	39	70	3	5	1	2
Genetic associates	20	34	36	61	3	5	0	0
Nurses	17	46	19	51	17	46	1	3
Social workers	4	67	1	17	1	17	0	0
Other PhD	4	25	10	63	1	6	1	6

Note: percentages may not add up to 100 due to rounding;  
 Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-38. Use videos and/or films (n = 174).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	6	11	18	32	13	23	19	34
Genetic associates	4	7	17	29	16	27	22	37
Nurses	2	5	15	41	12	32	8	22
Social workers	0	0	3	50	1	17	2	33
Other PhD	4	25	10	63	1	6	1	6

Note: percentages may not add up to 100 due to rounding;  
Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-39. Ask the patient to repeat what you said in his/her own words (n = 172).

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	8	15	34	18	8	15	5	9
Genetic associates	9	16	32	55	10	17	7	12
Nurses	12	32	21	57	2	5	2	5
Social workers	4	67	1	17	0	0	1	17
Other PhD	2	13	10	63	4	25	0	0

Note: percentages may not add up to 100 due to rounding;  
Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-40. Assess the need to see a social worker/mental health professional.

Professional	ALWAYS		SOMETIMES		RARELY		NEVER	
	no.	%	no.	%	no.	%	no.	%
Physicians	21	38	30	55	3	5	1	2
Genetic associates	14	24	33	56	9	15	3	5
Nurses	18	50	11	31	4	11	3	8
Social workers	3	50	3	50	0	0	0	0
Other PhD	2	13	10	63	4	25	0	0

Note: percentages may not add up to 100 due to rounding;  
 Physicians = all physicians; Genetic associates = all genetic associates; Nurses = all nurses MS.

Table 4-41. Omnibus test of Educational Methods and Principles.

Method	F-statistic	P
Ask patients their expectations of the counseling session	[F (2,150) = 0.66]	P = 0.52
Assess the patient's cultural beliefs	[F (2,150) = 0.21]	P = 0.80
Assess the patient's educational level	[F (2,150) = 0.83]	P = 0.43
Assess whether the patient is emotionally ready for the information	[F (2,150) = 3.03]	P = 0.051
Prepare the patient for the possibility of uncertain or shocking information	[F (2,150) = 2.57]	P = 0.07
Do individual counseling	[F (2,150) = 11.35]	P = 0.0001*
Do group counseling	[F (2,150) = 1.83]	P = 0.16
Use pre-tests and post-tests	[F (2,150) = 0.18]	P = 0.83
Assess readability level of written materials	[F (2,150) = 0.26]	P = 0.76
Use pamphlets/handouts	[F (2,150) = 2.95]	P = 0.055
Use videos/film	[F (2,150) = 0.78]	P = 0.46
Ask patient to repeat what was said in his/her own words	[F (2,150) = 3.19]	P = 0.044*
Assess the need to see social worker/mental health professional	[F (2,150) = 2.37]	P = 0.09

\* significant

Table 4-42. Post-hoc comparisons of significant findings of educational methods and principles by health professionals.

Method	no.	mean	P
<b>Do individual counseling</b>			
Physicians	56	3.71 ± 0.59	
Genetic counselors	58	3.86 ± 0.34	P >.05
Nurses	38	3.23 ± 0.97	
Genetic counselors	58	3.86 ± 0.34	P >.05*
Physicians	56	3.71 ± 0.59	
Nurses	58	3.23 ± 0.97	P <.05*
<b>Ask the patient to repeat what was said in his/her own words</b>			
Physicians	55	2.81 ± 0.79	
Genetic counselors	58	2.74 ± 0.86	P >.05
Nurses	37	3.16 ± 0.76	
Genetic counselors	58	2.74 ± 0.86	P <.05*
Physicians	55	2.81 ± 0.79	
Nurses	58	3.16 ± 0.76	P >.05

\* significant

#### Factors Perceived To Increase Counseling Effectiveness

Respondents were asked if the following factors increased their counseling effectiveness: gender; racial/ethnic background; having children; not having children; personal experience with genetic disorders; recognizing professional limitations; formal training in counseling techniques; formal training in educational methods and principles; and formal training in human genetics. Contingency tables and  $\chi^2$  tests were used for bivariate analyses (Table 4-43).

Seventy percent of all respondents did not perceive gender as a factor in increasing counseling effectiveness. Eighty-eight percent of all respondents did not perceived race as a factor in increasing counseling effectiveness. Fifty-seven percent did not perceive having children as a factor in increasing counseling effectiveness; however 56% of physicians considered it a factor. All respondents perceived not having children as a factor that did not increase counseling effectiveness.

Fifty-nine percent of all respondents did not perceive personal experience with genetic disorders as a factor in increasing counseling effectiveness; however, 53% of all physicians considered it a factor. Sixty-four percent of all respondents perceived recognizing one's professional limitation was a factor in increasing counseling effectiveness.

Fifty-one percent of all respondents did not perceive formal training in counseling techniques as a factor in increasing counseling effectiveness. 73% of genetic counselors considered it a factor. Seventy-six percent of all respondents did not perceived formal training in educational methods and principles as a factor in increasing counseling effectiveness. Sixty-eighth percent of all respondents perceived formal training in human genetics a factor in

Table 4-43. Factors perceived to increase counseling effectiveness:  $\chi^2$  analysis.

Factor	Yes		No		$\chi^2$	P
	no.	%	no.	%		
<b>Gender</b>						
Physicians	15	23	42	74		
Genetic associates	24	40	36	60		
Nurses	14	33	29	64	$[\chi^2 (2), n = 160 = 2.47]$	$P = 0.289$
<b>Race</b>						
Physicians	4	7	53	93		
Genetic associates	8	13	52	87		
Nurses	7	16	36	84	$[\chi^2 (2), n = 160 = 2.04]$	$P = 0.332$
<b>Having children</b>						
Physicians	32	56	25	44		
Genetic associates	16	27	44	73		
Nurses	20	47	23	53	$[\chi^2 (2), n = 160 = 10.77]$	$P = 0.005*$
<b>Not having children</b>						
Physicians	0	0	57	100		
Genetic associates	0	0	60	100		
Nurses	0	0	43	100	[n = 160]	
<b>Personal experience with a disorder</b>						
Physicians	30	53	27	47		
Genetic associates	17	28	43	72		
Nurses	18	42	25	58	$[\chi^2 (2), n = 160 = 7.19]$	$P = 0.003*$

Table 4-43--continued.

Factor	Yes no.	%	No no.	%	$\chi^2$	P
Recognizing professional limitation						
Physicians	35	61	22	39		
Genetic associates	39	65	21	35		
Nurses	28	65	15	35	$[\chi^2 (2), n = 160 = 0.21]$	$P = 0.900$
Formal training in counseling tech.						
Physicians	17	30	40	70		
Genetic associates	44	73	16	27		
Nurses	18	42	23	48	$[\chi^2 (2), n = 160 = 23.46]$	$P = 0.000*$
Formal training in education meth.						
Physicians	10	18	47	82		
Genetic associates	23	38	37	62		
Nurses	8	19	35	81	$[\chi^2 (2), n = 160 = 8.15]$	$P = 0.017*$
Formal training in human genetics						
Physicians	41	72	16	28		
Genetic associates	53	88	7	12		
Nurses	15	35	28	65	$[\chi^2 (2), n = 160 = 35.54]$	$P = 0.000*$

\* significant

increasing counseling effectiveness; however, 65% of nurses did not consider it a factor.

#### Factors Perceived To Limit Counseling Effectiveness

Respondents were asked if the following factors limited their counseling effectiveness: gender; racial/ethnic background; having children; not having children; no personal experience with genetic disorders; not recognizing professional limitations; no formal training in counseling techniques; no formal training in educational methods and principles; and no formal training in human genetics. Contingency tables and  $\chi^2$  tests were used for bivariate analyses (Table 4-44).

Eighty-six percent of all respondents did not perceive gender as a factor in limiting counseling effectiveness. Seventy nine percent of all respondents did not perceive race as a factor in limiting counseling effectiveness.

All respondents perceived having children as a factor that did not limiting counseling effectiveness. Seventy-one percent of all respondents did not perceive being childless as factor in limiting counseling effectiveness.

Having no personal experience with genetic disorders was not considered a factor in limiting counseling effectiveness by 80% of all respondents. Ninety-three percent of all respondents said not recognizing one's professional was not a factor in limiting counseling.

Ninety-three percent of all respondents did not perceive no formal training in counseling techniques as a factor in limiting counseling effectiveness. Eight-five percent of all respondents did not perceive no formal training in educational methods and principles as a factor in limiting counseling effectiveness. Eighty nine percent of all respondents did not perceive no formal training in human genetics as a factor in limiting counseling effectiveness.

#### Roles In The Counseling Process: Who Routinely Does What?

Respondents were asked to indicate who in their facility routinely carries out 30 genetic counseling-related activities. Contingency tables and  $\chi^2$  tests were used for bivariate analyses (Table 4-54).

#### Physicians

Two physician-related variables were deleted from physician analysis: clarify what the physicians says; and reinforce what the physicians says.

All physicians reported that they do not routinely refer patients to a social worker or other mental health professional. More than 60% reported that they routinely perform all but 2 of the other 27 genetic counseling-related activities: educate the patient on what to expect in the counseling session; and help families evaluate the impact of each potential outcome on the family. Forty to forty-nine percent reported that they routinely perform all

Table 4-44. Factors perceived to limit counseling effectiveness:  $\chi^2$  analysis.

Factor	Yes		No		$\chi^2$	P
	no.	%	no.	%		
<b>Gender</b>						
Physicians	12	21	45	79		
Genetic associates	9	15	51	85		
Nurses	2	5	41	95	$\chi^2$ (2), n = 160 = 5.39]	P = 0.068
<b>Race</b>						
Physicians	11	19	46	81		
Genetic associates	21	35	39	65		
Nurses	2	5	41	95	$\chi^2$ (2), n = 160 = 13.99]	P = 0.001*
<b>Having children</b>						
Physicians	0	0	57	100		
Genetic associates	2	3	58	97		
Nurses	0	0	43	100	[50% of cells 5<; $\chi^2$ not valid]	
<b>Not having children</b>						
Physicians	7	12	50	88		
Genetic associates	20	33	40	67		
Nurses	4	9	39	91	$\chi^2$ (2), n = 160 = 12.11]	P = 0.002*
<b>No personal experience with a disorder</b>						
Physicians	8	14	49	86		
Genetic associates	20	33	40	67		
Nurses	4	9	39	91	$\chi^2$ (2), n = 160 = 11.01]	P = 0.004*

Table 4-44--continued.

Factor	Yes		No		$\chi^2$	P
	no.	%	no.	%		
Not recognizing professional limitation						
Physicians	4	7	53	93		
Genetic associates	6	10	54	90		
Nurses	1	2	42	98	[50% of cells 5<; $\chi^2$ not valid]	
No formal training in counseling tech.						
Physicians	9	16	48	84		
Genetic associates	7	12	53	83		
Nurses	10	23	33	77	[ $\chi^2$ (2), n = 160 = 2.49]	P = 0.289
No formal training in education meth.						
Physicians	8	14	49	86		
Genetic associates	8	13	52	87		
Nurses	8	19	35	81	[ $\chi^2$ (2), n = 160 = 0.61]	P = 0.737
No formal training in human genetics						
Physicians	6	11	51	89		
Genetic associates	2	3	58	97		
Nurses	10	23	33	77	[ $\chi^2$ (2), n = 160 = 10.00]	P = 0.007*

\* significant

but 3 of the other 27 genetic counseling-related activities: identify the patients' coping strategies; help patient identify their support systems; and act as liaisons between patients and outside agencies (Table 4-45).

All genetic counselors reported that physicians do not routinely refer patients to a social worker or other mental health professional. The majority reported that physicians routinely perform only 12 of the other genetic counseling-related factors: assess the patients' understanding about the disorder; provide accurate and complete information about the disorder; describe diagnostic procedures; discuss the benefits and limitations of each procedure; discuss the diagnosis and prognosis; discuss the impact of the disorder on the family; discuss the available reproductive options; assess the need for follow-up visits; help the client move toward the chosen course of action; teach patients how to manage the disorder; alleviate the patients feelings of guilt, anxiety, or other expressed emotion; and assess the need to see a social worker or other mental health professional (Table 4-46).

Forty to 50% of genetic counselors reported that physicians routinely perform only 4 of the 28 genetic counseling-related activities: assess the patients' knowledge about the disorder; help the family hypothesize a variety of outcomes; ask patients their preferred course of action; and be physically available during crisis periods (Table 4-46).

All nurses reported that physicians did not routinely refer patients to a social worker or other mental health professional. The majority reported that physicians routinely perform all but 8 of the other 27 genetic counseling-related activities: educate patients on what to expect in the counseling session; construct pedigrees; obtain informed consent; identify the patients' coping strategies; help patients identify their support systems; help families evaluate the impact of each potential disorder; act as liaisons between patients and outside agencies; and develop patient education materials (4-47).

Forty to 50% of nurses said physicians routinely perform all but 2 of the other 27 genetic counseling-related variables: identify the patients' coping strategies; and help the patients identify their support systems (Table 4-47).

The only physician variable that did not depend on the different health professional was: physicians routinely assess the need for follow-up visits ( $P > .05$ ) (Table 4-54).

Table 4-45. What physicians say they routinely do and should do (n = 57).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	39%	61%	44%	56%
Construct a pedigree	72%	28%	56%	44%

Table 4-45--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Assess the patient's knowledge about the disorder	93%	7%	75%	25%
Assess the patient's understanding about the disorder	93%	7%	82%	18%
Provide accurate and complete information about the disorder	95%	5%	88%	12%
Describe diagnostic procedures	96%	4%	96%	4%
Discuss the benefits and limitations of each procedure	93%	7%	84%	16%
Obtain informed consent for diagnostic procedures	79%	21%	72%	28%
Call the patient at home when a diagnosis is made	79%	21%	68%	32%
Discuss the diagnosis and prognosis with the patient	95%	5%	86%	14%
Clarify what the physician says about the disorder	-	-	-	-
Reinforce what the physician says about the disorder	-	-	-	-
Identify the patient's coping strategies	61%	39%	56%	44%
Help the patient to identify his/her support systems	56%	44%	49%	51%
Discuss the impact of the disorder on the family	84%	16%	75%	25%
Discuss the available reproductive options	87%	13%	79%	21%
Assess the need for follow-up visits	91%	9%	84%	16%

Table 4-45--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	74%	26%	65%	35%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	74%	26%	63%	37%
Help the family evaluate the impact of each potential outcome on the family	39%	61%	63%	37%
Ask the patient his/her preferred course of action	79%	21%	81%	19%
Help the client move toward the chosen course of action	89%	11%	79%	21%
Teach patient how to manage the disorder	88%	12%	88%	12%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	84%	16%	75%	25%
Be emotionally available during crisis periods	84%	16%	74%	26%
Be physically available during crisis periods	86%	14%	74%	26%
Assess the need to see a social worker/mental health professional	89%	11%	84%	16%
Refer the patient to a social worker/mental health professional	0%	100%	81%	19%
Act as liaison between the patient and outside agencies	54%	46%	54%	46%
Develop patient education materials	70%	30%	65%	35%

Table 4-46. What genetic counselors say physicians do and should do (n = 60).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	15%	85%	25%	75%
Construct a pedigree	25%	75%	28%	72%
Assess the patient's knowledge about the disorder	50%	50%	42%	58%
Assess the patient's understanding about the disorder	55%	45%	53%	47%
Provide accurate and complete information about the disorder	78%	22%	87%	13%
Describe diagnostic procedures	58%	42%	58%	42%
Discuss the benefits and limitations of each procedure	57%	43%	63%	37%
Obtain informed consent for diagnostic procedures	33%	67%	47%	53%
Call the patient at home when a diagnosis is made	37%	63%	57%	43%
Discuss the diagnosis and prognosis with the patient	77%	23%	78%	22%
Clarify what the physician says about the disorder	-	-	-	-
Reinforce what the physician says about the disorder	-	-	-	-
Identify the patient's coping strategies	28%	72%	32%	68%
Help the patient to identify his/her support systems	30%	70%	82%	18%
Discuss the impact of the disorder on the family	52%	48%	50%	50%

Table 4- 46--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Discuss the available reproductive options	53%	47%	62%	38%
Assess the need for follow-up visits	80%	20%	78%	22%
Help the patient to recognize and to understand the emotional, cultural and religious factors that influence decision-making	30%	70%	35%	65%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	40%	60%	48	52%
Help the family evaluate the impact of each potential outcome on the family	15%	85%	48%	52%
Ask the patient his/her preferred course of action	40%	60%	55%	45%
Help the client move toward the chosen course of action	55%	45%	57%	63%
Teach patient how to manage the disorder	78%	22%	80%	20%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	95%	5%	90%	10%
Be emotionally available during crisis periods	30%	70%	48%	52%
Be physically available during crisis periods	40%	60%	52%	48%
Assess the need to see a social worker/mental health professional	67%	33%	68%	32%

Table 4-46--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Refer the patient to a social worker/mental health professional	0%	100%	83%	17%
Act as liaison between the patient and outside agencies	28%	71%	30%	70%
Develop patient education materials	17%	83%	43%	57%

Table 4-47 . What nurses say physicians do and should do (n = 43).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	21%	79%	19%	81%
Construct a pedigree	28%	72%	49%	51%
Assess the patient's knowledge about the disorder	63%	37%	51%	49%
Assess the patient's understanding about the disorder	67%	33%	56%	44%
Provide accurate and complete information about the disorder	86%	14%	56%	44%
Describe diagnostic procedures	77%	23%	77%	23%
Discuss the benefits and limitations of each procedure	79%	21%	77%	23%
Obtain informed consent for diagnostic procedures	30%	70%	53%	47%

Table 4-47--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Call the patient at home when a diagnosis is made	60%	40%	65%	35%
Discuss the diagnosis and prognosis with the patient	81%	19%	79%	21%
Clarify what the physician says about the disorder	-	-	-	-
Reinforce what the physician says about the disorder	-	-	-	-
Identify the patient's coping strategies	42%	58%	42%	58%
Help the patient to identify his/her support systems	40%	60%	26%	74%
Discuss the impact of the disorder on the family	65%	35%	49%	51%
Discuss the available reproductive options	74%	26%	53%	47%
Assess the need for follow-up visits	74%	26%	67%	33%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	56%	44%	49%	51%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	60%	40%	44%	56%
Help the family evaluate the impact of each potential outcome on the family	21%	79%	44%	56%
Ask the patient his/her preferred course of action	51%	49%	67%	33%

Table 4-47--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Help the client move toward the chosen course of action	77%	23%	44%	56%
Teach patient how to manage the disorder	65%	35%	58%	42%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	77%	23%	63%	37%
Be emotionally available during crisis periods	51%	49%	58%	42%
Be physically available during crisis periods	44%	56%	56%	44%
Assess the need to see a social worker/mental health professional	65%	35%	65%	35%
Refer the patient to a social worker/mental health professional	0%	100%	67%	33%
Act as liaison between the patient and outside agencies	28%	72%	26%	74%
Develop patient education materials	37%	63%	67%	33%

### Genetic counselors

All genetic counselors reported that they do not routinely refer patients to a social worker or other mental health professional; and do not routinely clarify what the physician says about the disorder. Eighty percent or more indicated that they routinely perform all but 1 of the other

28 genetic counseling-related activity: assess the patients' knowledge about the disorder. Fifty percent reported that they routinely teach patients how to manage the disorder; but 50% disagreed.

All physicians reported that genetic counselors do not routinely refer patients to a social worker or other mental health professional; and do not routinely clarify what the physician says about the disorder. The majority reported that genetic counselors do not routinely perform 12 of the other 28 genetic counseling-related activities: assess the patients' knowledge about the disorder; obtain informed consent; educated patients on what to expect in the counseling session; assess the patients' understanding about the disorder; provide accurate and complete information about the disorder; describe diagnostic procedures; discuss the benefits and limitations of each procedure; discuss the diagnosis and prognosis with the patient; assess the need for follow-up visits; help families hypothesize a variety of outcomes; help families evaluate the impact of each potential outcome; ask patients their preferred course of action; help clients move toward their chosen course of action; teach patients to manage the disorder; and assess the need to see a social worker or other mental health professional.

Forty to 49% of physicians said genetic counselors do not routinely perform 10 of the genetic counseling-related activities: describe diagnostic procedures; call patients at

home when a diagnosis is made; discuss the impact of the disorder on the family; discuss the available reproductive options; help the family to recognize and to understand the emotional, cultural, and religious factors that influence decision-making; help the client move toward the chosen course of action; alleviate the patients' feelings of guilt, anxiety, or other emotion expressed; be emotionally available; be physically available; and act as liaisons between patients and outside agencies.

More than 60% of nurses said the only genetic counseling-related activities that genetic counselors routinely perform was reinforcing what the physicians said about the disorder. Fifty percent or more of nurses reported that genetic counselors did not routinely perform the other genetic counseling-related activities.

Two genetic counselor variables did not depend on the different health professional: 1) genetic counselors did not routinely assessed the patients' knowledge about the disorder ( $P > .05$ ); and 2) genetic counselors did not routinely teach patients how to manage the disorder ( $P > .05$ ) (Table 4-54).

Table 4-48. What genetic counselors say they routinely do and should do (n = 60).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	90%	10%	85%	15%
Construct a pedigree	97%	3%	97%	3%
Assess the patient's knowledge about the disorder	18%	82%	92%	8%
Assess the patient's understanding about the disorder	95%	5%	95%	5%
Provide accurate and complete information about the disorder	92%	8%	92%	8%
Describe diagnostic procedures	92%	8%	92%	8%
Discuss the benefits and limitations of each procedure	92%	8%	92%	8%
Obtain informed consent for diagnostic procedures	93%	7%	87%	13%
Call the patient at home when a diagnosis is made	87%	13%	88%	12%
Discuss the diagnosis and prognosis with the patient	92%	8%	87%	13%
Clarify what the physician says about the disorder	0	100	93%	7%
Reinforce what the physician says about the disorder	90%	10%	90%	10%
Identify the patient's coping strategies	95%	5%	87%	13%
Help the patient to identify his/her support systems	95%	5%	82%	18%
Discuss the impact of the disorder on the family	90%	10%	87%	13%

Table 4-48--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Discuss the available reproductive options	93%	7%	93%	7%
Assess the need for follow-up visits	82%	18%	83%	17%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	90%	10%	90%	10%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	90%	10%	92%	8%
Help the family evaluate the impact of each potential outcome on the family	88%	12%	92%	8%
Ask the patient his/her preferred course of action	90%	10%	90%	10%
Help the client move toward the chosen course of action	88%	12%	88%	12%
Teach patient how to manage the disorder	50%	50%	67%	23%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	95%	5%	90%	10%
Be emotionally available during crisis periods	95%	5%	88%	12%
Be physically available during crisis periods	77%	23%	78%	22%

Table 4-48 --continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Assess the need to see a social worker/mental health professional	83%	17%	92%	8%
Refer the patient to a social worker/mental health professional	0%	100%	67%	33%
Act as liaison between the patient and outside agencies	85%	15%	87%	13%
Develop patient education materials	92%	8%	95%	5%

Table 4-49. What physicians say genetic counselors do and should do (n = 57).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	49%	51%	63%	37%
Construct a pedigree	61%	39%	74%	26%
Assess the patient's knowledge about the disorder	11%	89%	58%	42%
Assess the patient's understanding about the disorder	54%	55%	46%	54%
Provide accurate and complete information about the disorder	49%	51%	46%	54%
Describe diagnostic procedures	51%	49%	51%	49%
Discuss the benefits and limitations of each procedure	42%	58%	42%	58%

Table 4-49 --continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Obtain informed consent for diagnostic procedures	33%	67%	42%	58%
Call the patient at home when a diagnosis is made	58%	42%	60%	40%
Discuss the diagnosis and prognosis with the patient	44%	56%	47%	53%
Clarify what the physician says about the disorder	0%	100%	65%	35%
Reinforce what the physician says about the disorder	67%	35%	67%	33%
Identify the patient's coping strategies	61%	39%	72%	28%
Help the patient to identify his/her support systems	61%	39%	68%	32%
Discuss the impact of the disorder on the family	54%	46%	67%	33%
Discuss the available reproductive options	54%	46%	60%	40%
Assess the need for follow-up visits	47%	53%	49%	51%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	60%	40%	72%	28%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	49%	51%	67	33%
Help the family evaluate the impact of each potential outcome on the family	49%	51%	67%	33%

Table 4-49 --continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Ask the patient his/her preferred course of action	49%	51%	53%	47%
Help the client move toward the chosen course of action	51%	49%	65%	35%
Teach patient how to manage the disorder	44%	56%	47%	53%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	58%	42%	72%	28%
Be emotionally available during crisis periods	58%	42%	70%	30%
Be physically available during crisis periods	56%	44%	63%	37%
Assess the need to see a social worker/mental health professional	46%	54%	53%	47%
Refer the patient to a social worker/mental health professional	0%	100%	51%	49%
Act as liaison between the patient and outside agencies	54%	46%	67%	33%
Develop patient education materials	74%	26%	60%	40%

Table 4-50. What nurses say genetic counselors do and should do (n = 43).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	37%	63%	49%	51%
Construct a pedigree	49%	51%	67%	33%
Assess the patient's knowledge about the disorder	28%	72%	60%	40%
Assess the patient's understanding about the disorder	49%	51%	65%	35%
Provide accurate and complete information about the disorder	40%	60%	56%	44%
Describe diagnostic procedures	37%	63%	37%	63%
Discuss the benefits and limitations of each procedure	40%	60%	51%	49%
Obtain informed consent for diagnostic procedures	35%	65%	49%	51%
Call the patient at home when a diagnosis is made	35%	65%	37%	63%
Discuss the diagnosis and prognosis with the patient	30%	70%	49%	51%
Clarify what the physician says about the disorder	0%	100%	60%	40%
Reinforce what the physician says about the disorder	63%	37%	63%	37%
Identify the patient's coping strategies	40%	60%	58%	42%
Help the patient to identify his/her support systems	47%	53%	56%	44%
Discuss the impact of the disorder on the family	49%	51%	58%	42%

Table 4-50--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Discuss the available reproductive options	42%	58%	51%	49%
Assess the need for follow-up visits	27%	63%	49%	51%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	40%	60%	56%	44%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	37%	63%	60%	40%
Help the family evaluate the impact of each potential outcome on the family	44%	56%	60%	40%
Ask the patient his/her preferred course of action	47%	53%	51%	49%
Help the client move toward the chosen course of action	47%	53%	53%	47%
Teach patient how to manage the disorder	30%	70%	47%	53%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	47%	53%	60%	40%
Be emotionally available during crisis periods	40%	60%	51%	49%
Be physically available during crisis periods	35%	65%	42%	58%

Table 4-50 --continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Assess the need to see a social worker/mental health professional	37%	63%	56%	44%
Refer the patient to a social worker/mental health professional	0%	100%	58%	42%
Act as liaison between the patient and outside agencies	37%	63%	42%	58%
Develop patient education materials	40%	60%	67%	33%

### Nurses

All nurses reported that they do not routinely refer patients to a social worker or other mental health professional. The majority reported that they routinely perform all but 5 of the other 29 genetic counseling-related activities: provide accurate and complete information about the disorder; discuss the benefits and limitations of each procedure; discuss the diagnosis and prognosis; discuss the available reproductive options; and help families evaluate the impact of each potential outcome.

Forty to 49% of nurses reported that routinely perform all but 9 of the other 29 genetic counseling-related variables: assess the patient's understanding of the disorder; describe diagnostic procedures; call patients at home when a diagnosis is made; assess the need for follow-up visits; help

the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making; ask patients their preferred course of action; help the clients move toward the chosen course of action; be physically available during crisis periods; develop educational material (Table 4-51).

All physicians said that nurses routinely assess the patients' knowledge about the disorder. Fifty percent or more of physicians indicated that nurses do not routinely perform the other genetic counseling-related activities (Table 4-52).

All genetic counselors said that nurses routinely assess the patients' knowledge about the disorder. Sixty percent or more of genetic counselors indicated that nurses do not routinely perform the other genetic counseling-related activities (Table 4-53).

All nurse variables depended on the different health professional ( $P < .05$ )

#### Social workers

Sixty percent or more of physicians, genetic counselors, and nurses said social workers do not routinely perform any of the genetic counseling-related activities (Table 4-54).

Table 4-51. What nurses say they routinely do and should do (n = 43).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	79%	21%	81%	19%
Construct a pedigree	79%	21%	65%	35%
Assess the patient's knowledge about the disorder	100%	0%	70%	30%
Assess the patient's understanding about the disorder	56%	44%	65%	35%
Provide accurate and complete information about the disorder	42%	58%	47%	53%
Describe diagnostic procedures	58%	42%	58%	42%
Discuss the benefits and limitations of each procedure	37%	63%	47%	53%
Obtain informed consent for diagnostic procedures	63%	37%	63%	37%
Call the patient at home when a diagnosis is made	54%	46%	44%	56%
Discuss the diagnosis and prognosis with the patient	35%	65%	33%	67%
Clarify what the physician says about the disorder	81%	19%	74%	26%
Reinforce what the physician says about the disorder	77%	23%	77%	23%
Identify the patient's coping strategies	79%	21%	63%	37%
Help the patient to identify his/her support systems	79%	21%	63%	27%
Discuss the impact of the disorder on the family	74%	26%	63%	37%

Table 4-51--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Discuss the available reproductive options	44%	56%	56%	44%
Assess the need for follow-up visits	51%	49%	56%	44%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	53%	47%	56%	44%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	79%	21%	54%	46%
Help the family evaluate the impact of each potential outcome on the family	44%	56%	53%	47%
Ask the patient his/her preferred course of action	51%	49%	60%	40%
Help the client move toward the chosen course of action	51%	49%	60%	40%
Teach patient how to manage the disorder	63%	37%	70%	30%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	74%	26%	70%	30%
Be emotionally available during crisis periods	72%	28%	70%	30%
Be physically available during crisis periods	60%	40%	60%	40%

Table 4-51--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Assess the need to see a social worker/mental health professional	70%	30%	72%	18%
Refer the patient to a social worker/mental health professional	0%	100%	72%	18%
Act as liaison between the patient and outside agencies	77%	23%	67%	33%
Develop patient education materials	58%	42%	26%	74%

Table 4-52. What physicians say nurses do and should do (n = 57).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	37%	63%	42%	58%
Construct a pedigree	36%	64%	74%	26%
Assess the patient's knowledge about the disorder	100%	11%	33%	67%
Assess the patient's understanding about the disorder	23%	77%	35%	65%
Provide accurate and complete information about the disorder	18%	82%	19%	81%
Describe diagnostic procedures	23%	67%	23%	67%
Discuss the benefits and limitations of each procedure	14%	86%	19%	81%

Table 4-52--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Obtain informed consent for diagnostic procedures	25%	75%	67%	33%
Call the patient at home when a diagnosis is made	18%	82%	25%	75%
Discuss the diagnosis and prognosis with the patient	9%	91%	21%	79%
Clarify what the physician says about the disorder	30%	70%	35%	65%
Reinforce what the physician says about the disorder	47%	53%	47%	53%
Identify the patient's coping strategies	32%	68%	40%	60%
Help the patient to identify his/her support systems	30%	70%	40%	60%
Discuss the impact of the disorder on the family	28%	72%	67%	33%
Discuss the available reproductive options	19%	81%	30%	70%
Assess the need for follow-up visits	21%	79%	28%	72%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	25%	75%	33%	67%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	19%	81%	32	68%
Help the family evaluate the impact of each potential outcome on the family	19%	81%	32%	68%

Table 4-52--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Ask the patient his/her preferred course of action	23%	77%	28%	72%
Help the client move toward the chosen course of action	19%	81%	32%	68%
Teach patient how to manage the disorder	26%	74%	40%	60%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	21%	79%	40%	60%
Be emotionally available during crisis periods	28%	72%	40%	60%
Be physically available during crisis periods	30%	70%	39%	61%
Assess the need to see a social worker/mental health professional	33%	67%	42%	58%
Refer the patient to a social worker/mental health professional	0%	100%	39%	61%
Act as liaison between the patient and outside agencies	32%	68%	46%	54%
Develop patient education materials	33%	67%	46%	54%

Table 4-53. What genetic counselors say nurses routinely do and should do (n = 57).

Activity	Do		Should do	
	Yes	No	Yes	No
Educate the patient on what to expect in the counseling session	13%	87%	33%	67%
Construct a pedigree	13%	87%	20%	80%
Assess the patient's knowledge about the disorder	100%	0%	17%	83%
Assess the patient's understanding about the disorder	17%	83%	13%	87%
Provide accurate and complete information about the disorder	12%	88%	13%	87%
Describe diagnostic procedures	18%	82%	18%	82%
Discuss the benefits and limitations of each procedure	15%	85%	27%	73%
Obtain informed consent for diagnostic procedures	27%	63%	32%	68%
Call the patient at home when a diagnosis is made	15%	85%	20%	80%
Discuss the diagnosis and prognosis with the patient	13%	87%	20%	80%
Clarify what the physician says about the disorder	18%	82%	22%	78%
Reinforce what the physician says about the disorder	32%	68%	32%	68%
Identify the patient's coping strategies	12%	88%	25%	75%
Help the patient to identify his/her support systems	17%	83%	25%	75%
Discuss the impact of the disorder on the family	17%	83%	25%	75%

Table 4-53--continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Discuss the available reproductive options	17%	83%	32%	68%
Assess the need for follow-up visits	15%	85%	22%	78%
Help the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making	25%	75%	17%	83%
Help the family hypothesize a variety of outcomes based on possible family planning decisions	13%	87%	17%	83%
Help the family evaluate the impact of each potential outcome on the family	12%	88%	17%	83%
Ask the patient his/her preferred course of action	13%	87%	17%	83%
Help the client move toward the chosen course of action	15%	85%	18%	82%
Teach patient how to manage the disorder	25%	75%	37%	63%
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	17%	83%	33%	67%
Be emotionally available during crisis periods	22%	78%	28%	72%
Be physically available during crisis periods	20%	80%	27%	73%

Table 4-53 --continued.

Activity	Do		Should do	
	Yes	No	Yes	No
Assess the need to see a social worker/mental health professional	0%	100%	21%	78%
Refer the patient to a social worker/mental health professional	0%	100%	35%	65%
Act as liaison between the patient and outside agencies	13%	87%	27%	73%
Develop patient education materials	10%	90%	33%	67%

### Roles In The Counseling Process: Who Should Be Doing?

Respondents were asked to indicate who in their facility routinely carries out 30 genetic counseling-related activities. Contingency tables and  $\chi^2$  tests were used for bivariate analyses (Table 4-55)

#### Physicians

Two physician-related variables were deleted from physician analysis: clarify what the physicians says; and reinforce what the physicians says.

The majority of physicians reported that they should be performing all but 2 of the other 28 genetic counseling-related activities: educating patients on what to expect in the counseling session; and helping patients identify their support system. Forty to 49% indicated that they should be performing all but 2 of the other 28 genetic counseling-related activities: educating patients on what to expect in the counseling session; and helping patients identify their support system. (Table 4-45).

The majority of genetic counselors indicated that physicians should perform all but 10 of the 30 genetic counseling related activities: assessing the patients' knowledge about the disorder; obtaining informed consent; identifying the patients' coping strategies; helping patients to recognize and to understand the emotional, cultural, and religious factors that influence decision-making; helping the family to hypothesize a variety of outcomes; being emotionally

available; acting as liaisons between patients and outside agencies; and developing patient education materials (4-46).

Forty to 50% of genetic counselors indicated that physicians should perform all but 7 of the 30 genetic counseling related activities: assessing the patients' knowledge about the disorder; obtaining informed consent; discussing the impact of the disorder on the family; helping the family to hypothesize a variety of outcomes; being emotionally available; and developing patient education materials (4-46).

The majority of nurses indicated that physicians should be performing only 10 of the 30 genetic counseling-related activities: educating patients on what to expect in the counseling session; constructing pedigrees; identifying the patients' coping strategies; helping patients to identify their support systems; discussing the impact of the disorder on the family; helping patients to recognize and to understand the emotional, cultural, and religious factors that influence decision-making; helping families to hypothesize a variety of outcomes; helping families to evaluate the impact of each potential outcome; and acting as liaisons between patients and outside agencies (Table 4-47).

Forty to 49% of nurses indicated that physicians should perform only 7 of the 30 genetic counseling-related activities: constructing pedigrees; identifying the patients' coping strategies; discussing the impact of the disorder on

the family; helping patients to recognize and to understand the emotional, cultural, and religious factors that influence decision-making; helping families to hypothesize a variety of outcomes; and helping families to evaluate the impact of each potential outcome (Table 4-47).

Responses to 10 physician variables did not depend on the different health professional: provide accurate and complete information about the disorder; calls patients at home when a diagnosis is made; discuss the diagnosis and prognosis; reinforces what the physician says about the disorder; assess the need for follow-up visits; help families hypothesize a variety of outcomes; alleviate feelings of guilt, anxiety, or other expressed emotions; be physically available during crisis periods; assess the need to see a social worker or other mental health professional; refer patients to a social worker or other mental health professional ( $P > .05$ ) (Table 4-55).

#### Genetic Counselors

More than 65% of genetic counselors reported that they should perform all 30 genetic counseling-related activities (Table 4-48).

The majority of physicians indicated that genetic counselors should perform all but 7 of the 30 genetic counseling-related activities: assessing the patients' understanding of the disorder; providing accurate and complete information about the disorder; discussing the benefits and

limitations of each procedure; obtaining informed consent; discussing the diagnosis and prognosis; assessing the need for follow-up visits; and teach patients how to manage the disorder (Table 4-49).

Forty to 49% of physicians indicated that genetic counselors should perform all but 7 of the 30 genetic counseling-related activities: assessing the patients' understanding of the disorder; providing accurate and complete information about the disorder; discussing the benefits and limitations of each procedure; obtaining informed consent; discussing the diagnosis and prognosis; assessing the need for follow-up visits; and teach patients how to manage the disorder (Table 4-49).

The majority of nurses indicated that genetic counselors should perform all but 9 of the 30 genetic counseling-related activities: educating patients on what to expect in the counseling session; describing diagnostic procedures; obtaining informed consent; discussing the diagnosis and prognosis; calling patients at home when a diagnosis is made; assessing the need for follow-up visits; teaching patients how to manage the disorder; being physically available during crisis periods; and acting as liaisons between patients and outside agencies. (Table 4-50).

Forty to 49% of nurses indicated that genetic counselors should perform only 7 of the 30 genetic counseling related activities: educating patients on what to expect in the

counseling session; obtaining informed consent; discussing the diagnosis and prognosis; assessing the need for follow-up visits; teaching patients how to manage the disorder; being physically available during crisis periods; and acting as liaisons between patients and outside agencies. (Table 4-50).

Only one genetic counselor variable did not depend on the different health professionals. Sixty-seven percent of genetic counselors believed they should teach patients how to manage the disorder; but 53% of physicians and 53% of nurses disagreed ( $P = .054$ ) (Table 4-55).

#### Nurses

The majority of nurses indicated that they should perform all but 5 of the 30 genetic counseling-related factors: providing accurate and complete information about the disorder; discussing the benefits and limitation of each procedure; calling patients at home when a diagnosis is made; discussing the diagnosis and prognosis; and developing patient education materials (Table 4-51).

Forty to 49% of nurses indicated that they should perform all but 3 of the 30 genetic counseling-related activities: providing accurate and complete information about the disorder; discussing the benefits and limitation of each procedure; and calling patients at home when a diagnosis is made; discussing the diagnosis and prognosis (Table 4-51).

More than 60% of physicians indicated that nurses should do only 3 of the 30 genetic counseling-related activities:

constructing pedigrees; obtaining informed consent; and discussing the impact of the disorder on the family (Table 4-52).

Forty to 49% of physicians indicated that nurses should perform only 10 of the 30 genetic counseling-related activities: educating patients on what to expect in the counseling session; reinforcing what the physicians says in the counseling session; identifying the patients' coping strategies; helping patients to identify their support systems; teaching patients how to manage their disorder; alleviating the patients' feelings of guilt, anxiety, or other expressed emotion; being emotionally available during crisis periods; assessing the need to see a social worker or other mental health professional; acting as liaisons between patients and outside agencies; and developing patient education materials (Table 4-52).

Sixty percent or more of genetic counselors indicated that nurses should not do any of the 30 genetic counseling-related activities (Table 4-53).

All nurse variables depended on the different health professionals ( $P < .05$ ) (Table 4-55).

#### Social Workers

Sixty percent or more of physicians, and almost 60% of genetic counselors and nurses indicated that social workers should not perform any of the 30 genetic counseling-related activities (4-55).

Table 4-54. Who routinely does the following activities in your facility?  $\chi^2$  analysis.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Educates the patient on what to expect in the counseling sess.								
Physicians	22/39	35/61	9/15	51/85	9/21	34/79	$[\chi^2(2), n = 160 = 9.20]$	$P = 0.010^*$
Genetic As.	28/49	12/51	54/90	6/10	16/37	27/63	$[\chi^2(2), n = 160 = 34.89]$	$P = 0.000^*$
Nurses	21/37	36/63	8/13	52/87	34/79	9/21	$[\chi^2(2), n = 160 = 45.58]$	$P = 0.000^*$
Social Work.	3/5	54/95	1/2	59/98	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	
Constructs pedigree								
Physicians	41/72	16/28	15/25	45/75	12/28	31/72	$[\chi^2(2), n = 160 = 31.47]$	$P = 0.000^*$
Genetic As.	35/61	22/39	58/97	2/3	21/49	22/51	$[\chi^2(2), n = 160 = 32.17]$	$P = 0.000^*$
Nurses	17/30	40/70	8/13	52/87	34/79	9/21	$[\chi^2(2), n = 160 = 48.39]$	$P = 0.000^*$
Social Work.	4/7	53/93	1/2	59/98	0/0	43/100	[50% of cells 5<; $\chi^2$ not valid]	
Assesses knowledge about disorder								
Physicians	53/93	4/7	30/50	30/50	27/63	16/37	$[\chi^2(2), n = 160 = 26.11]$	$P = 0.000^*$
Genetic As.	6/11	51/89	11/18	49/82	12/28	31/72	$[\chi^2(2), n = 160 = 4.99]$	$P = 0.082$
Nurses	11/100	0/0	11/100	0/0	31/100	0/0	[n = 53]	
Social Work.	0/0	57/100	0/0	60/100	2/5	41/95	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
<b>Assesses understanding of disorder</b>								
Physicians	53/93	4/7	33/55	27/45	29/67	14/33	$\chi^2(2)$ , n = 160 = 21.43]	P = 0.000*
Genetic As.	31/54	26/55	57/95	3/5	21/49	22/51	$\chi^2(2)$ , n = 160 = 32.28]	P = 0.000*
Nurses	13/23	44/77	10/17	50/83	24/56	19/44	$\chi^2(2)$ , n = 160 = 20.34]	P = 0.000*
Social Work.	3/5	54/95	1/2	59/98	2/5	41/95	[50% of cells 5<; $\chi^2$ not valid]	
<b>Provides information about disorder</b>								
Physicians	54/95	3/5	47/78	13/22	37/86	6/14	$\chi^2(2)$ , n = 160 = 6.63]	P = 0.036*
Genetic As.	28/49	29/51	55/92	5/8	17/40	26/60	$\chi^2(2)$ , n = 160 = 35.81]	P = 0.000*
Nurses	10/18	47/82	7/12	53/88	18/42	25/58	$\chi^2(2)$ , n = 160 = 14.47]	P = 0.001*
Social Work.	1/2	56/98	1/2	59/98	0/0	43/100	[50% of cells 5<; $\chi^2$ not valid]	
<b>Describes diagnostic procedures</b>								
Physicians	55/96	2/4	35/58	25/42	33/77	10/23	$\chi^2(2)$ , n = 160 = 23.94]	P = 0.000*
Genetic As.	29/51	28/49	55/92	5/8	16/37	27/63	$\chi^2(2)$ , n = 160 = 36.79]	P = 0.000*
Nurses	13/23	44/67	11/18	49/82	25/58	18/42	$\chi^2(2)$ , n = 160 = 21.22]	P = 0.000*
Social Work.	2/4	55/96	0/0	60/100	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Describes benefits and limitations of procedures								
Physicians	53/93	4/7	34/57	26/43	34/79	9/21	$[\chi^2(2), n = 160 = 21.29]$	$P = 0.000^*$
Genetic As.	24/42	33/58	55/92	5/8	17/40	26/60	$[\chi^2(2), n = 160 = 40.18]$	$P = 0.000^*$
Nurses	8/14	49/86	9/15	51/85	16/37	27/63	$[\chi^2(2), n = 160 = 9.89]$	$P = 0.000^*$
Social Work.	2/4	55/96	0/0	60/100	0/0	43/100	[50% of cells 5<; $\chi^2$ not valid]	
Obtains informed consent								
Physicians	45/79	12/21	20/33	40/67	13/30	30/70	$[\chi^2(2), n = 160 = 32.41]$	$P = 0.000^*$
Genetic As.	19/33	38/67	56/93	4/7	15/35	28/65	$[\chi^2(2), n = 160 = 53.67]$	$P = 0.000^*$
Nurses	14/25	43/75	16/27	44/73	27/63	16/37	$[\chi^2(2), n = 160 = 18.97]$	$P = 0.000^*$
Social Work.	3/5	54/95	1/2	59/98	0/0	43/100	[50% of cells 5<; $\chi^2$ not valid]	
Calls patient at home when diagnosis is made								
Physicians	45/79	12/21	22/37	38/63	26/60	17/40	$[\chi^2(2), n = 160 = 21.60]$	$P = 0.000^*$
Genetic As.	33/58	24/42	52/87	8/13	15/35	65/65	$[\chi^2(2), n = 160 = 39.46]$	$P = 0.000^*$
Nurses	10/18	47/82	9/15	51/85	23/54	20/46	$[\chi^2(2), n = 160 = 22.63]$	$P = 0.000^*$
Social Work.	3/5	54/95	1/2	59/98	0/0	43/100	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
<b>Discusses diagnosis and prognosis</b>								
Physicians	54/95	3/5	46/77	14/23	35/81	8/19	$[\chi^2(2), n = 160 = 7.63]$	$P = 0.022^*$
Genetic As.	25/44	32/56	55/92	5/8	13/30	30/70	$[\chi^2(2), n = 160 = 46.24]$	$P = 0.000^*$
Nurses	5/9	52/91	8/13	52/87	15/35	28/65	$[\chi^2(2), n = 160 = 12.72]$	$P = 0.002^*$
Social Work.	1/2	56/98	2/3	58/97	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	
<b>Clarifies what the physician says</b>								
Physicians	24/42	33/58	9/10	54/90	5/12	38/88	$[\chi^2(2), n = 160 = 21.24]$	$P = 0.000^*$
Genetic As.	0/0	24/100	0/0	3/100	0/0	23/100	[n = 160]	
Nurses	17/30	40/70	11/18	49/82	35/81	8/19	$[\chi^2(2), n = 160 = 45.11]$	$P = 0.000^*$
Social Work.	8/14	49/86	8/13	52/87	3/7	40/93	$[\chi^2(2), n = 160 = 1.37]$	$P = 0.506$
<b>Reinforces what the physician says</b>								
Physicians	20/35	37/65	10/17	50/83	9/21	34/79	$[\chi^2(2), n = 160 = 5.76]$	$P = 0.056$
Genetic As.	38/67	19/33	54/90	6/10	27/63	16/37	$[\chi^2(2), n = 160 = 12.49]$	$P = 0.002^*$
Nurses	27/47	30/53	19/32	41/68	33/77	10/23	$[\chi^2(2), n = 160 = 20.50]$	$P = 0.000^*$
Social Work.	8/14	48/86	8/13	52/87	3/7	40/93	$[\chi^2(2), n = 160 = 1.37]$	$P = 0.506$

Table 4-54--continued.

Activity	Physicians		Genetic assoc. Nurses		$\chi^2$	P		
	Yes/%	No/%	Yes/%	No/%				
<b>Identifies patient's coping strategies</b>								
Physicians	35/61	22/39	17/28	43/72	18/42	25/58	$[\chi^2(2), n = 160 = 13.08]$	$P = 0.001*$
Genetic As.	35/61	22/39	57/95	3/5	17/40	26/60	$[\chi^2(2), n = 160 = 37.33]$	$P = 0.000*$
Nurses	18/32	39/68	7/12	53/88	34/79	9/21	$[\chi^2(2), n = 160 = 49.96]$	$P = 0.000*$
Social Work.	11/19	46/81	5/9	55/92	3/7	40/93	$[\chi^2(2), n = 160 = 4.71]$	$P = 0.095$
<b>Helps patient identify support system</b>								
Physicians	22/56	25/43	18/30	42/70	17/40	26/60	$[\chi^2(2), n = 160 = 8.34]$	$P = 0.015*$
Genetic As.	35/61	22/39	57/95	3/5	20/47	23/53	$[\chi^2(2), n = 160 = 31.16]$	$P = 0.000*$
Nurses	17/30	40/70	10/17	50/83	34/79	9/21	$[\chi^2(2), n = 160 = 43.93]$	$P = 0.000*$
Social Work.	12/21	45/79	7/12	53/88	5/12	38/88	$[\chi^2(2), n = 160 = 2.54]$	$P = 0.280$
<b>Discusses impact of disorder on family</b>								
Physicians	48/84	9/16	31/52	29/48	28/65	15/35	$[\chi^2(2), n = 160 = 14.06]$	$P = 0.001*$
Genetic As.	31/54	26/46	54/90	6/10	21/49	22/51	$[\chi^2(2), n = 160 = 24.56]$	$P = 0.000*$
Nurses	16/28	41/72	10/17	50/83	32/74	11/26	$[\chi^2(2), n = 160 = 38.72]$	$P = 0.000*$
Social Work.	11/19	46/81	5/8	55/92	4/9	39/91	$[\chi^2(2), n = 160 = 3.76]$	$P = 0.152$

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Discusses reproduc-								
tive options								
Physicians	50/87	7/13	32/53	28/47	32/74	11/26	$[\chi^2(2), n = 160 = 17.16]$	$P = 0.000^*$
Genetic As.	31/54	26/46	55/92	5/8	18/42	25/58	$[\chi^2(2), n = 160 = 31.69]$	$P = 0.000^*$
Nurses	11/19	46/81	10/17	50/83	19/44	24/56	$[\chi^2(2), n = 160 = 11.65]$	$P = 0.003^*$
Social Work.	3/5	54/95	3/5	57/95	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	
Assesses need for								
follow-up visits								
Physicians	52/91	5/9	48/80	12/20	32/74	11/26	$[\chi^2(2), n = 160 = 5.21]$	$P = 0.074$
Genetic As.	27/47	30/53	49/82	11/18	16/37	27/63	$[\chi^2(2), n = 160 = 23.98]$	$P = 0.000^*$
Nurses	12/21	45/79	9/15	51/85	22/51	21/49	$[\chi^2(2), n = 160 = 18.19]$	$P = 0.000^*$
Social Work.	5/9	52/91	1/2	59/99	2/5	41/95	$[\chi^2(2), n = 160 = 3.12]$	$P = 0.210$
Helps patient recognize								
and understand factors								
that influence decision								
Physicians	42/74	15/26	18/30	42/70	24/56	19/44	$[\chi^2(2), n = 160 = 22.63]$	$P = 0.000^*$
Genetic As.	34/60	23/40	54/90	6/10	17/40	26/60	$[\chi^2(2), n = 160 = 29.31]$	$P = 0.000^*$
Nurses	14/25	43/75	8/13	52/87	23/53	20/47	$[\chi^2(2), n = 160 = 20.53]$	$P = 0.000^*$
Social Work.	9/16	48/84	3/5	57/95	3/7	40/93	$[\chi^2(2), n = 160 = 4.40]$	$P = 0.111$

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Helps family hypothesize variety of outcomes								
Physicians	42/74	15/26	24/40	36/60	26/60	17/40	$[\chi^2(2), n = 160 = 13.78]$	$P = 0.001^*$
Genetic As.	28/49	29/51	54/90	6/10	16/37	27/63	$[\chi^2(2), n = 160 = 34.89]$	$P = 0.000^*$
Nurses	11/19	46/89	8/13	52/87	34/79	9/21	$[\chi^2(2), n = 160 = 45.58]$	$P = 0.000^*$
Social Work.	3/5	54/95	1/2	59/98	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	
Helps family evaluate the impact of outcome								
Physicians	22/39	35/61	9/15	51/85	9/21	34/79	$[\chi^2(2), n = 160 = 9.20]$	$P = 0.010^*$
Genetic As.	28/49	29/51	53/88	7/12	19/44	24/56	$[\chi^2(2), n = 160 = 27.59]$	$P = 0.000^*$
Nurses	11/19	46/81	7/12	53/88	19/44	24/56	$[\chi^2(2), n = 160 = 15.63]$	$P = 0.000^*$
Social Work.	3/5	54/95	1/2	59/98	2/5	41/95	$[\chi^2(2), n = 160 = 1.18]$	$P = 0.554$
Asks patient the preferred action								
Physicians	45/79	12/21	24/40	36/60	22/51	21/49	$[\chi^2(2), n = 160 = 18.86]$	$P = 0.000^*$
Genetic As.	28/49	29/51	54/90	6/10	20/47	23/53	$[\chi^2(2), n = 160 = 28.69]$	$P = 0.000^*$
Nurses	13/23	44/77	8/13	52/87	22/51	21/49	$[\chi^2(2), n = 160 = 18.98]$	$P = 0.000^*$
Social Work.	7/12	50/88	3/5	57/95	5/12	38/88	$[\chi^2(2), n = 160 = 2.17]$	$P = 0.337$

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Helps patient move toward action								
Physicians	51/89	6/11	33/55	27/45	33/77	10/23	$[\chi^2(2), n = 160 = 18.07]$	$P = 0.000^*$
Genetic As.	29/51	28/49	53/88	7/12	20/47	23/53	$[\chi^2(2), n = 160 = 23.31]$	$P = 0.000^*$
Nurses	11/19	46/81	9/15	51/85	22/51	21/49	$[\chi^2(2), n = 160 = 19.13]$	$P = 0.000^*$
Social Work.	3/5	54/95	2/3	58/97	3/7	40/93	[50% of cells 5<; $\chi^2$ not valid]	
Teaches patient how to manage disorder								
Physicians	50/88	7/12	47/78	13/22	28/65	15/35	$[\chi^2(2), n = 160 = 7.33]$	$P = 0.026^*$
Genetic As.	25/44	30/56	30/50	30/50	13/30	30/70	$[\chi^2(2), n = 160 = 4.07]$	$P = 0.131^*$
Nurses	15/26	42/74	15/25	45/75	27/63	16/37	$[\chi^2(2), n = 160 = 18.94]$	$P = 0.000^*$
Social Work.	5/9	52/91	3/5	57/95	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	
Alleviates feelings of guilt, anxiety, etc.								
Physicians	48/84	9/16	33/55	27/45	33/77	10/23	$[\chi^2(2), n = 160 = 13.04]$	$P = 0.001^*$
Genetic As.	33/58	24/42	57/95	3/5	20/47	23/53	$[\chi^2(2), n = 160 = 32.27]$	$P = 0.000^*$
Nurses	12/21	45/79	10/17	50/83	32/74	11/26	$[\chi^2(2), n = 160 = 43.75]$	$P = 0.000^*$
Social Work.	10/18	47/82	5/8	55/92	4/9	39/91	$[\chi^2(2), n = 160 = 2.74]$	$P = 0.254$

Table 4-54--continued.

Activity	Physicians		Genetic assoc. Nurses		$\chi^2$	P		
	Yes/%	No/%	Yes/%	No/%				
<b>Is emotionally available during crisis</b>								
Physicians	48/84	9/16	18/30	42/70	22/51	21/49	$[\chi^2(2), n = 160 = 35.06]$	P = 0.000*
Genetic As.	33/58	24/42	57/95	3/5	17/40	26/60	$[\chi^2(2), n = 160 = 38.01]$	P = 0.000*
Nurses	16/28	41/72	13/22	47/78	31/72	12/28	$[\chi^2(2), n = 160 = 30.54]$	P = 0.000*
Social Work.	22/39	35/61	7/12	53/88	4/9	39/91	$[\chi^2(2), n = 160 = 17.55]$	P = 0.000*
<b>Is physically available during crisis</b>								
Physicians	49/86	8/14	24/40	36/60	19/44	24/56	$[\chi^2(2), n = 160 = 29.54]$	P = 0.000*
Genetic As.	32/56	25/44	46/77	14/23	15/35	28/65	$[\chi^2(2), n = 160 = 18.11]$	P = 0.000*
Nurses	17/30	40/70	12/20	48/80	26/60	17/40	$[\chi^2(2), n = 160 = 18.99]$	P = 0.000*
Social Work.	12/21	45/79	7/12	53/88	5/12	38/88	$[\chi^2(2), n = 160 = 2.54]$	P = 0.280
<b>Assesses need to see social worker</b>								
Physicians	51/89	6/11	40/67	20/33	28/65	15/35	$[\chi^2(2), n = 160 = 10.62]$	P = 0.005*
Genetic As.	26/46	31/54	50/83	10/17	16/37	27/63	$[\chi^2(2), n = 160 = 26.93]$	P = 0.000*
Nurses	19/33	38/67	9/15	51/85	30/70	13/30	$[\chi^2(2), n = 160 = 32.84]$	P = 0.000*
Social Work.	5/9	52/91	1/2	59/98	3/7	40/93	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-54--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Refers patient to social worker								
Physicians	0/0	57/100	0/0	60/100	0/0	43/100	[n = 160]	
Genetic As.	0/0	57/100	0/0	60/100	0/0	43/100	[n = 160]	
Nurses	0/0	57/100	0/0	60/100	0/0	43/100	[n = 160]	
Social Work.	0/0	57/100	0/0	60/100	0/2	43/9100	[n = 160]	
Acts as liaison between patient and agencies								
Physicians	31/54	26/46	17/28	43/71	12/28	31/72	[ $\chi^2(2)$ , n = 160 = 10.77]	P = 0.005*
Genetic As.	31/54	26/46	51/85	9/15	16/37	27/63	[ $\chi^2(2)$ , n = 160 = 25.86]	P = 0.000*
Nurses	18/32	39/68	8/13	52/87	33/77	10/23	[ $\chi^2(2)$ , n = 160 = 45.34]	P = 0.000*
Social Work.	13/23	44/77	9/15	51/85	7/16	36/84	[ $\chi^2(2)$ , n = 160 = 1.33]	P = 0.513
Develops patient education materials								
Physicians	40/70	17/30	10/17	50/83	16/37	27/63	[ $\chi^2(2)$ , n = 160 = 34.93]	P = 0.000*
Genetic As.	34/60	23/40	55/92	5/8	17/40	26/60	[ $\chi^2(2)$ , n = 160 = 32.17]	P = 0.000*
Nurses	19/33	38/67	6/10	54/90	25/58	18/42	[ $\chi^2(2)$ , n = 160 = 27.19]	P = 0.000*
Social Work.	4/7	53/93	2/3	58/97	2/5	41/95	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-55. Who should do the following activities in your facility?  $\chi^2$  analysis.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Educate the patient on what to expect in the counseling sess.								
Physicians	25/44	32/56	15/25	45/75	8/19	35/81	$[\chi^2(2), n = 160 = 8.59]$	$P = 0.014^*$
Genetic As.	36/63	21/37	51/85	9/15	21/49	22/51	$[\chi^2(2), n = 160 = 15.69]$	$P = 0.000^*$
Nurses	24/42	33/58	20/33	40/67	35/81	8/19	$[\chi^2(2), n = 160 = 25.02]$	$P = 0.000^*$
Social Work.	7/12	50/88	7/53	59/98	5/12	38/88	$[\chi^2(2), n = 160 = 0.01]$	$P = 0.993$
Construct pedigree								
Physicians	32/56	25/44	17/28	43/72	11/26	32/74	$[\chi^2(2), n = 160 = 13.21]$	$P = 0.001^*$
Genetic As.	42/74	15/26	58/97	2/3	29/67	14/33	$[\chi^2(2), n = 160 = 16.43]$	$P = 0.000^*$
Nurses	19/33	38/67	12/20	48/80	28/65	15/35	$[\chi^2(2), n = 160 = 22.38]$	$P = 0.000^*$
Social Work.	3/5	54/95	3/5	57/95	1/2	42/100	[50% of cells 5<; $\chi^2$ not valid]	
Assess knowledge about disorder								
Physicians	43/75	14/25	25/42	35/58	22/51	21/49	$[\chi^2(2), n = 160 = 14.17]$	$P = 0.001^*$
Genetic As.	33/58	24/42	55/92	5/8	26/60	17/40	$[\chi^2(2), n = 160 = 19.61]$	$P = 0.000^*$
Nurses	19/33	38/67	10/17	50/83	30/70	13/30	$[\chi^2(2), n = 160 = 30.82]$	$P = 0.000^*$
Social Work.	6/11	51/89	4/7	56/93	2/5	41/95	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-55---continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
<b>Assess understanding of disorder</b>								
Physicians	47/82	10/18	32/53	28/47	24/56	19/44	$[\chi^2(2), n = 160 = 12.69]$	$P = 0.002^*$
Genetic As.	32/56	25/44	57/95	3/5	28/65	15/35	$[\chi^2(2), n = 160 = 24.65]$	$P = 0.000^*$
Nurses	20/35	37/65	10/17	50/83	28/65	15/35	$[\chi^2(2), n = 160 = 25.49]$	$P = 0.000^*$
Social Work.	4/7	53/93	2/3	58/97	3/7	40/93	[50% of cells 5<; $\chi^2$ not valid]	
<b>Provide information about disorder</b>								
Physicians	50/88	7/12	52/87	8/13	37/86	6/14	$[\chi^2(2), n = 160 = 0.064]$	$P = 0.969$
Genetic As.	26/46	31/54	55/92	5/8	24/56	19/55	$[\chi^2(2), n = 160 = 29.99]$	$P = 0.000^*$
Nurses		11/19	46/18	8/13	52/87	20/47	23/53	$[\chi^2(2), n = 160 = 29.99]$
Social Work.		1/2	56/98	1/2	59/98	2/5	41/95	[50% of cells 5<; $\chi^2$ not valid]
<b>Describe diagnostic procedures</b>								
Physicians	55/96	2/4	35/58	25/42	33/77	10/23	$[\chi^2(2), n = 160 = 23.94]$	$P = 0.000^*$
Genetic As.	29/51	28/49	55/92	5/8	16/37	27/63	$[\chi^2(2), n = 160 = 36.79]$	$P = 0.000^*$
Nurses	13/23	44/67	11/18	49/82	25/58	18/42	$[\chi^2(2), n = 160 = 21.22]$	$P = 0.000^*$
Social Work.	2/4	55/96	0/0	60/100	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-55--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
<u>Describes benefits and limitations of procedures</u>								
Physicians	48/84	9/16	38/63	22/37	33/77	10/23	$[\chi^2(2), n = 160 = 6.86]$	$P = 0.032^*$
Genetic As.	24/42	33/58	55/92	5/8	22/51	21/49	$[\chi^2(2), n = 160 = 34.46]$	$P = 0.000^*$
Nurses	11/19	46/81	16/27	44/73	20/47	23/53	$[\chi^2(2), n = 160 = 9.09]$	$P = 0.011^*$
Social Work.	1/2	56/98	0/0	60/100	1/2	42/98	[50% of cells 5<; $\chi^2$ not valid]	
<u>Obtains informed consent</u>								
Physicians	41/72	16/28	28/47	32/53	23/53	20/47	$[\chi^2(2), n = 160 = 8.02]$	$P = 0.018^*$
Genetic As.	24/42	33/58	52/87	8/13	21/49	22/51	$[\chi^2(2), n = 160 = 27.74]$	$P = 0.000^*$
Nurses	19/33	38/67	19/32	41/68	27/63	16/37	$[\chi^2(2), n = 160 = 12.01]$	$P = 0.002^*$
Social Work.	2/4	55/96	2/3	58/98	3/7	40/93	[50% of cells 5<; $\chi^2$ not valid]	
<u>Calls patient at home when diagnosis is made</u>								
Physicians	39/68	18/32	34/57	26/43	28/65	15/35	$[\chi^2(2), n = 160 = 1.84]$	$P = 0.399$
Genetic As.	34/60	23/40	53/88	7/12	16/37	27/63	$[\chi^2(2), n = 160 = 29.41]$	$P = 0.000^*$
Nurses	14/25	43/75	12/20	48/80	19/44	24/56	$[\chi^2(2), n = 160 = 7.81]$	$P = 0.020^*$
Social Work.	5/9	52/91	2/3	58/97	3/7	40/93	[50% of cells 5<; $\chi^2$ not valid]	

Table 4-55--continued.

Activity	Physicians		Genetic assoc. Nurses		$\chi^2$	P		
	Yes/%	No/%	Yes/%	No/%				
Discuss diagnosis and prognosis								
Physicians	49/86	8/14	47/78	13/22	34/79	9/21	$[\chi^2(2), n = 160 = 1.30]$	$P = 0.552$
Genetic As.	27/47	30/53	52/87	8/13	21/49	22/51	$[\chi^2(2), n = 160 = 23.94]$	$P = 0.000*$
Nurses	12/21	45/79	12/20	48/80	14/33	29/67	$[\chi^2(2), n = 160 = 2.54]$	$P = 0.281$
Social Work.	1/2	56/98	2/3	58/97	2/5	41/95	[50% of cells 5<; $\chi^2$ not valid]	
Clarify what the physician says								
Physicians	24/42	33/58	10/17	50/83	10/23	33/77	$[\chi^2(2), n = 160 = 10.02]$	$P = 0.007*$
Genetic As.	37/65	20/35	56/93	4/7	26/60	17/40	$[\chi^2(2), n = 160 = 18.34]$	$P = 0.000*$
Nurses	20/35	37/65	13/22	47/78	32/74	11/26	$[\chi^2(2), n = 160 = 30.02]$	$P = 0.000*$
Social Work.	7/12	50/88	4/7	56/93	2/5	41/95	$[\chi^2(2), n = 160 = 1.37]$	$P = 0.506$
Reinforce what the physician says								
Physicians	20/35	37/65	10/17	50/83	9/21	34/71	$[\chi^2(2), n = 160 = 5.76]$	$P = 0.056$
Genetic As.	38/67	19/33	54/90	6/10	27/63	16/37	$[\chi^2(2), n = 160 = 12.49]$	$P = 0.002*$
Nurses	27/47	30/53	19/32	41/68	33/77	10/23	$[\chi^2(2), n = 160 = 20.50]$	$P = 0.000*$
Social Work.	8/14	48/86	8/13	52/87	3/7	40/93	$[\chi^2(2), n = 160 = 1.37]$	$P = 0.506$

Table 4-55--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Identify patient's coping strategies								
Physicians	32/56	25/44	19/32	41/68	18/42	25/58	$[\chi^2(2), n = 160 = 7.18]$	$P = 0.028^*$
Genetic As.	41/72	16/28	52/87	8/13	25/58	25/42	$[\chi^2(2), n = 160 = 10.68]$	$P = 0.005^*$
Nurses	23/40	34/60	15/25	45/75	28/65	15/35	$[\chi^2(2), n = 160 = 16.66]$	$P = 0.000^*$
Social Work.	22/39	35/61	25/42	35/58	12/28	31/72	$[\chi^2(2), n = 160 = 2.15]$	$P = 0.341$
Help patient identify support system								
Physicians	28/49	29/51	15/25	45/75	11/26	32/74	$[\chi^2(2), n = 160 = 9.36]$	$P = 0.009^*$
Genetic As.	39/68	18/32	49/82	11/18	24/56	19/44	$[\chi^2(2), n = 160 = 8.08]$	$P = 0.018^*$
Nurses	23/40	34/60	15/25	45/75	27/63	16/27	$[\chi^2(2), n = 160 = 14.83]$	$P = 0.001^*$
Social Work.	23/40	34/60	26/43	34/47	15/35	28/65	$[\chi^2(2), n = 160 = 0.75]$	$P = 0.687$
Discuss impact of disorder on family								
Physicians	43/75	14/25	30/50	30/50	21/49	22/51	$[\chi^2(2), n = 160 = 10.19]$	$P = 0.006^*$
Genetic As.	38/67	19/33	52/87	8/13	25/58	18/42	$[\chi^2(2), n = 160 = 11.27]$	$P = 0.004^*$
Nurses	21/37	36/63	15/25	45/75	27/63	16/37	$[\chi^2(2), n = 160 = 15.22]$	$P = 0.000^*$
Social Work.	20/35	37/65	19/32	41/68	15/35	28/65	$[\chi^2(2), n = 160 = 0.19]$	$P = 0.911$

Table 4-55--continued.

Activity	Physicians		Genetic assoc. Nurses		$\chi^2$	P		
	Yes/%	No/%	Yes/%	No/%				
<b>Discuss reproductive options</b>								
Physicians	45/79	12/21	37/62	23/38	23/53	20/47	$[\chi^2(2), n = 160 = 7.71]$	$P = 0.021^*$
Genetic As.	34/60	23/40	56/93	4/7	22/51	21/49	$[\chi^2(2), n = 160 = 25.73]$	$P = 0.000^*$
Nurses	17/30	40/70	19/32	41/68	24/56	19/44	$[\chi^2(2), n = 160 = 8.46]$	$P = 0.015^*$
Social Work.	7/12	50/88	10/17	50/83	2/5	41/95	$[\chi^2(2), n = 160 = 3.47]$	$P = 0.176$
<b>Assess need for follow-up visits</b>								
Physicians	48/84	9/16	47/78	13/22	29/67	14/33	$[\chi^2(2), n = 160 = 3.99]$	$P = 0.136$
Genetic As.	28/49	29/51	50/83	10/17	21/49	22/51	$[\chi^2(2), n = 160 = 18.74]$	$P = 0.000^*$
Nurses	16/28	41/72	13/22	47/78	24/56	19/44	$[\chi^2(2), n = 160 = 14.21]$	$P = 0.001^*$
Social Work.	8/14	49/86	10/17	50/83	4/9	39/91	$[\chi^2(2), n = 160 = 1.15]$	$P = 0.562$
<b>Help patient recognize and understand factors that influence decision</b>								
Physicians	37/65	20/35	21/35	39/65	21/49	22/51	$[\chi^2(2), n = 160 = 10.47]$	$P = 0.005^*$
Genetic As.	41/72	16/28	54/90	6/10	24/56	19/44	$[\chi^2(2), n = 160 = 15.64]$	$P = 0.000^*$
Nurses	19/33	38/67	10/17	50/83	24/56	19/44	$[\chi^2(2), n = 160 = 17.33]$	$P = 0.000^*$
Social Work.	18/32	39/68	19/32	41/68	12/28	31/72	$[\chi^2(2), n = 160 = 0.21]$	$P = 0.903$

Table 4-55--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Help family hypothesize variety of outcomes								
Physicians	36/63	21/37	29/48	31/52	19/44	24/56	$[\chi^2(2), n = 160 = 4.21]$	$P = 0.122$
Genetic As.	38/67	19/33	55/92	5/8	26/60	17/40	$[\chi^2(2), n = 160 = 15.64]$	$P = 0.000*$
Nurses	18/32	39/68	10/17	50/83	23/54	20/46	$[\chi^2(2), n = 160 = 15.64]$	$P = 0.000*$
Social Work.	16/28	41/72	23/38	37/62	17/40	26/60	$[\chi^2(2), n = 160 = 1.89]$	$P = 0.390$
Help family evaluate the impact of outcome								
Physicians	36/63	21/37	29/48	31/52	19/44	24/56	$[\chi^2(2), n = 160 = 4.21]$	$P = 0.012*$
Genetic As.	38/67	19/33	55/92	5/8	26/60	17/40	$[\chi^2(2), n = 160 = 15.56]$	$P = 0.000*$
Nurses	18/32	39/68	10/17	50/83	23/53	20/47	$[\chi^2(2), n = 160 = 15.64]$	$P = 0.000*$
Social Work.	16/28	41/72	23/38	37/62	17/40	26/60	$[\chi^2(2), n = 160 = 1.89]$	$P = 0.390$
Ask patient the preferred action								
Physicians	46/81	11/19	33/55	27/45	29/67	14/33	$[\chi^2(2), n = 160 = 8.80]$	$P = 0.012*$
Genetic As.	30/53	27/47	54/90	6/10	22/51	21/49	$[\chi^2(2), n = 160 = 24.24]$	$P = 0.000*$
Nurses	16/28	41/72	10/17	50/83	26/60	17/40	$[\chi^2(2), n = 160 = 22.69]$	$P = 0.000*$
Social Work.	9/16	48/84	7/12	53/88	10/23	33/77	$[\chi^2(2), n = 160 = 2.49]$	$P = 0.289$

Table 4-55--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Help patient move toward action								
Physicians	45/79	12/21	34/57	26/43	19/44	24/56	$[\chi^2(2), n = 160 = 13.33]$	$P = 0.001*$
Genetic As.	37/65	20/35	53/88	7/12	23/53	20/47	$[\chi^2(2), n = 160 = 16.05]$	$P = 0.000*$
Nurses	18/32	39/68	11/18	49/82	26/60	17/40	$[\chi^2(2), n = 160 = 20.02]$	$P = 0.000*$
Social Work.	14/25	43/75	12/20	48/80	12/28	31/72	$[\chi^2(2), n = 160 = 0.89]$	$P = 0.639$
Teach patient how to manage disorder								
Physicians	50/88	7/12	48/80	12/20	25/58	18/42	$[\chi^2(2), n = 160 = 12.59]$	$P = 0.002*$
Genetic As.	27/47	30/53	40/67	20/33	20/47	23/53	$[\chi^2(2), n = 160 = 5.85]$	$P = 0.054$
Nurses	23/40	34/60	22/37	38/63	30/70	13/30	$[\chi^2(2), n = 160 = 12.53]$	$P = 0.002*$
Social Work.	9/16	48/84	8/13	52/87	4/9	39/91	$[\chi^2(2), n = 160 = 0.90]$	$P = 0.635$
Alleviate feelings of guilt, anxiety, etc.								
Physicians	43/75	14/25	39/65	21/35	27/63	16/37	$[\chi^2(2), n = 160 = 2.23]$	$P = 0.327$
Genetic As.	41/72	16/28	54/90	6/10	26/60	17/40	$[\chi^2(2), n = 160 = 12.51]$	$P = 0.002*$
Nurses	23/40	34/60	20/33	40/67	30/70	13/30	$[\chi^2(2), n = 160 = 14.39]$	$P = 0.001*$
Social Work.	21/37	36/63	23/38	37/62	18/42	25/58	$[\chi^2(2), n = 160 = 0.27]$	$P = 0.875$

Table 4-55--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Be emotionally available during crisis								
Physicians	42/74	15/26	29/48	31/52	25/58	18/42	$[\chi^2(2), n = 160 = 7.91]$	$P = 0.019^*$
Genetic As.	40/70	17/30	53/88	7/12	22/51	21/49	$[\chi^2(2), n = 160 = 17.25]$	$P = 0.000^*$
Nurses	23/40	34/60	17/28	43/72	30/70	13/30	$[\chi^2(2), n = 160 = 17.89]$	$P = 0.000^*$
Social Work.	23/40	34/60	31/52	29/48	17/40	26/60	$[\chi^2(2), n = 160 = 2.07]$	$P = 0.354$
Be physically available during crisis								
Physicians	42/74	15/26	31/52	29/48	24/56	19/44	$[\chi^2(2), n = 160 = 6.51]$	$P = 0.039^*$
Genetic As.	36/63	21/37	47/78	13/22	18/42	25/58	$[\chi^2(2), n = 160 = 14.32]$	$P = 0.001^*$
Nurses	22/39	35/61	16/27	44/73	26/60	17/40	$[\chi^2(2), n = 160 = 11.99]$	$P = 0.002^*$
Social Work.	19/33	38/67	25/42	35/58	17/40	26/60	$[\chi^2(2), n = 160 = 0.91]$	$P = 0.634$
Asses need to see social worker								
Physicians	48/84	9/16	41/68	19/32	28/65	15/35	$[\chi^2(2), n = 160 = 5.67]$	$P = 0.059$
Genetic As.	30/53	27/47	55/92	5/8	24/56	19/44	$[\chi^2(2), n = 160 = 24.62]$	$P = 0.000^*$
Nurses	24/42	33/58	20/33	40/67	31/72	12/28	$[\chi^2(2), n = 160 = 15.92]$	$P = 0.000^*$
Social Work.	15/26	42/78	19/32	41/63	9/21	34/79	$[\chi^2(2), n = 160 = 1.48]$	$P = 0.476$

Table 4-55--continued.

Activity	Physicians		Genetic assoc.		Nurses		$\chi^2$	P
	Yes/%	No/%	Yes/%	No/%	Yes/%	No/%		
Refer patient to social worker								
Physicians	46/81	11/19	40/67	20/33	29/67	14/33	$[\chi^2(2), n = 160 = 3.42]$	$P = 0.181$
Genetic As.	29/51	28/49	50/83	10/17	23/58	18/42	$[\chi^2(2), n = 160 = 14.75]$	$P = 0.001^*$
Nurses	22/39	35/61	21/35	39/65	31/72	12/28	$[\chi^2(2), n = 160 = 15.95]$	$P = 0.000^*$
Social Work.	12/21	45/79	13/22	47/78	11/26	32/74	$[\chi^2(2), n = 160 = 0.33]$	$P = 0.849$
Act as liaison between patient and agencies								
Physicians	31/54	26/46	18/30	42/70	11/26	32/74	$[\chi^2(2), n = 160 = 10.98]$	$P = 0.004^*$
Genetic As.	38/67	19/33	52/87	8/13	18/42	25/58	$[\chi^2(2), n = 160 = 22.95]$	$P = 0.000^*$
Nurses	26/46	31/54	16/27	44/73	26/60	17/40	$[\chi^2(2), n = 160 = 12.06]$	$P = 0.002^*$
Social Work.	23/40	34/60	27/45	33/55	18/42	25/56	$[\chi^2(2), n = 160 = 0.87]$	$P = 0.874$
Develop patient education materials								
Physicians	37/65	20/35	26/43	34/57	29/67	14/33	$[\chi^2(2), n = 160 = 7.95]$	$P = 0.019^*$
Genetic As.	42/74	15/26	57/95	3/5	29/67	14/33	$[\chi^2(2), n = 160 = 14.09]$	$P = 0.001^*$
Nurses	26/46	31/54	20/33	40/67	29/67	14/33	$[\chi^2(2), n = 160 = 11.76]$	$P = 0.003^*$
Social Work.	13/23	44/77	18/30	42/70	11/26	32/74	$[\chi^2(2), n = 160 = 0.79]$	$P = 0.672$

### Relationship Between Who Does And Who Should Do Counseling

Contingency tables and  $\chi^2$  tests were used for bivariate analyses between who does genetic counseling and who should do genetic counseling. In these analysis, the high percentage of agreement (88% or higher) resulted in cells with expected counts less than five. Hence,  $\chi^2$  values may not be valid and are not reported (Table 4-56).

### Physicians

None of the physicians routinely refer patients to a social worker or other mental health professional; but 81% believed they should perform this activity. The majority physicians reported that they do not and should not routinely educate patients on what to expect in the counseling session. The majority reported that they routinely help patients identify their support systems but did not believe they should perform this activity. The majority of physicians indicated that they routinely do and should do the other 26 genetic counseling related activities (Table 4-45).

The majority of genetic counselors indicated that physicians do not and should not perform 10 genetic counseling-related activities: educate patients on what to expect in the counseling session; assess the patients' knowledge of the disorder; obtain informed consent; identify the patients' coping strategies; help patients to recognize and to understand the emotional, cultural, and religious factors that influence decision-making; help families evaluate

the impact of each potential outcome; be emotionally available during crisis periods; act as liaisons between patients and outside agencies; and develop patient education materials (Table 4-46).

All genetic counselors reported that physicians do not routinely refer patients to a social worker or other mental health professional; but 83% believed physicians should perform this activity. The majority of genetic counselors reported that physicians do not routinely do but should perform five other genetic counseling-related activities: call patients at home when a diagnosis is made; help patients identify their support systems; ask patients their preferred course of action; help clients move toward their preferred course of action; be physically available during crisis periods (Table 4-46).

The majority of genetic counselors indicated that physicians routinely discuss the impact of the disorder on the family; but 50% did not believe physicians should be performing this activity (Table 4-46).

All nurses reported that physicians do not routinely refer patients to see a social worker or other mental health professional; but 67% believed that physicians should perform this activity. The majority of nurses indicated that physicians do not but should perform two genetic counseling-related activities: obtain informed consent; and develop patient education materials (Table 4-47).

The majority of nurses reported that physicians do not and should not perform six genetic counseling related activities: educate patients on what to expect in the counseling session; construct pedigrees; identify the patients' coping strategies; help patients identify their support systems; help families evaluate the impact of each potential outcome; and act as liaisons between patients and outside agencies (Table 4-47).

#### Genetic Counselors

All genetic counselors reported that they do not routinely refer patients to see a social worker or other mental health professional; but 67 % believed they should perform this activity. All genetic counselors reported that they do not routinely clarify what physicians say about the disorder; but 93% believed they should perform this activity. Eighty-two percent reported that they do not routinely assess the patients' knowledge of the disorder; but 92% believed they should. Fifty percent reported that they do not routinely teach patients how to manage the disorder; but 67% believed they should perform this activity. Genetic counselors reported that they routinely do and should do the other genetic counseling-related activities (Table 4-48).

All physicians reported that genetic counselors do not routinely refer patients to see a social worker or other mental health professional; but 51% believed genetic counselors should perform this activity. All physicians

reported that genetic counselors do not routinely clarify what physicians say about the disorder; but 65% believed genetic counselors should perform this activity. The majority of physicians reported that genetic counselors do not but should perform five other genetic counseling related activities: educate patients on what to expect in the counseling session; assess the patients' knowledge of the disorder; help families hypothesize a variety of outcomes based on possible family planning decisions; help families evaluate the impact of each potential outcome; and ask patients their preferred course of action (Table 4-49).

The majority of physicians reported that genetic counselors do not and should not perform seven genetic counseling related activities: assess the patients' understanding of the disorder; discuss the benefits and limitations of each procedure; obtain informed consent; discuss the diagnosis and prognosis; assess the need for follow-up visits; and teach clients how to manage the disorder (Table 4-49).

All nurses reported that genetic counselors do not routinely refer patients to see a social worker or other mental health professional; but 58 % believed genetic counselors should perform this activity. All nurses reported that genetic counselors do not routinely clarify what physicians say about the disorder; but 60% believed genetic counselors should perform this activity (Table 4-50).

The majority of nurses reported that genetic counselors do not and should not perform nine genetic counseling-related activities: educate patients on what to expect in the counseling session; describe diagnostic procedures; obtain informed consent; call patients at home when a diagnosis is made; discuss the diagnosis and prognosis; assess the need for follow-up visits; teach patients how to manage the disorder; be physically available during crisis periods; and act as liaisons between patients and outside agencies (Table 4-50).

The majority of nurses reported that genetic counselors routinely do and should do only one genetic counseling-related activity: reinforce what the physicians says about the disorder. The majority of nurses indicated that genetic counselors do not but should perform the other 18 genetic counseling-related activities (Table 4-50).

#### Nurses

All nurses reported that they do not routinely refer patients to a social worker or other mental health worker; but 72% believe they should perform this activity. The majority of nurses indicated that they do not and should not perform two genetic counseling-related activities: provide accurate and complete information about the disorder; and discuss the benefits and limitations of each procedure. The majority of nurses reported that they routinely do but should not do two genetic counseling-related activities: call the patient at

home when a diagnosis is made; and develop patient education materials (Table 4-51).

The majority of physicians indicated that nurses do not but should construct pedigrees. The majority of physicians indicated that nurses routinely do but should not assess the patients' knowledge of the disorder. The majority of physicians indicated that nurses do not and should not perform the other 28 genetic counseling-related activities (Table 4-52).

All genetic counselors indicated that nurses routinely assess the patients' knowledge about the disorder; 83% do not believe that nurses should perform this activity. The majority of genetic counselors indicated that nurses do not and should not perform the other 29 genetic counseling-related activities (Table 4-53).

#### Professional Concerns

The majority of respondents (80%, n = 148) did not believe only master's trained genetic counselors (genetic associates) should do genetic counseling. They were more likely to work at university medical centers (62%) and in urban areas (72%). Those who believed only genetic associates should do genetic counseling (20%, n = 37) worked mainly in university medical centers (62%) and in urban areas (70%).

The majority of physicians (91%) did not believe only genetic associates should do genetic counseling. Forty-three percent of genetic associates with master's degrees

(n = 22) believed that they should be the only health professionals doing genetic counseling; 57% (n = 27) disagreed. All genetic associates with PhDs did not believe only genetic associates should do genetic counseling.

All nurses with master's degrees did not believe only genetic associates should do genetic counseling. Eighty-one percent of nurses with bachelor's degree (n = 26) did not believe only genetic associates should do genetic counseling; 19% (n = 6) disagreed. Eighty-three percent of social workers (n = 5) did not believe only genetic associates should do genetic counseling. All other health professionals with PhDs did not believe only genetic associates should do genetic counseling.

Table 4-56. Relationship between who does and who should do genetic counseling.

Activity	Agreement		Disagreement	
	no.	%	no.	%
Educate the patient on what to expect in the counseling session	157	95	9	5
Construct a pedigree	165	99	1	1
Assess knowledge about disorder	165	99	1	1

Table 4-56--continued.

Activity	Agreement		Disagreement	
	no.	%	no.	%
Assess understanding of disorder	165	100	0	0
Provide information about disorder	165	100	0	0
Describe diagnostic procedures	165	100	0	0
Describe benefits and limitations of procedures	164	99	2	1
Obtain informed consent	159	96	7	4
Call patient at home when diagnosis is made	158	95	8	5
Discuss diagnosis and prognosis	162	98	4	2
Clarify what the physician says	159	96	7	4
Reinforce what the physician says	160	96	6	4
Identify patient's coping strategies	163	98	3	2
Help patient identify support system	163	98	3	2
Discuss impact of disorder on family	164	99	2	1
Discuss reproductive options	164	99	2	1
Assess need for follow-up visits	165	99	1	1
Help patient recognize and understand factors that influence decision	156	94	10	6

Table 4-56--continued.

Activity	Agreement		Disagreement	
	no.	%	no.	%
Help family hypothesize variety of outcomes	161	97	5	3
Help family evaluate impact of outcome	0	0	7	100
Ask patient the preferred action	161	97	5	3
Help patient move toward action	158	95	1	5
Teach patient how to manage the disorder	157	95	9	5
Alleviate feelings of guilt, anxiety, etc.	164	99	2	1
Be emotionally available during crisis	162	98	4	2
Be physically available during crisis	153	92	13	8
Assess need to see social worker	161	98	4	2
Refer patient to social social worker	162	98	4	2
Act as liaison between patient and agencies	160	96	6	4
Develop patient education materials	146	88	20	12

Note: percentages may not add up to 100 due to rounding.

## Summary Of Major Findings

### Demographics

In the Southeastern United States, genetic counseling is carried out primarily by white women (63%). Genetic associates (32%), physicians (30%), and nurses (22%) are the three largest group of health professionals that do genetic counseling. Social workers (3%) are usually not involved in genetic counseling. Physicians have been involved in genetic counseling (13 years,  $sd \pm 9.7$ ) longer than genetic associates (6 years,  $\pm sd 4.5$ ), nurses (6 years,  $sd \pm 4.4$ ), and social workers (10 years,  $sd \pm 3.9$ ).

### Genetic Counseling Team

Genetic counseling professionals rarely work independently and genetic counseling is usually a team activity. The team usually consists of physician(s) and genetic counselor(s) (26% of the time); and physician(s), genetic counselor(s), and nurse(s) (16% of the time). Physicians are part of the genetic counseling team 80% of the time; genetic associates are part of the team 70% of the time; nurses are a part of the team 38% of the time; and social workers are part of the team 6% of the time.

### Facility And Patient Population

Genetic counseling is usually offered at university medical centers located in urban areas. Forty-eight percent

of respondents work at facilities that have three genetic associates; and 24% work at facilities that have one genetic associate.

Forty-five percent of respondents described their patient population as a mixture of pediatric and prenatal clients; 20% as prenatal; 18% as general public; 12% as pediatric; and 4% as other.

Professional Preparation: Human Genetics

Fifty-three percent of all respondents reported that they had college course work in human genetics, supervised clinical training, and seminar/workshop training. Fifty-six percent of physicians, 93% of genetic counselors; and 36% of nurses had training in all three areas. Eleven percent of physicians had additional fellowship training.

Table 4-57 Training in human genetics

Preparation	MD	GC	RN
Course Work in Human Genetics	62%	98%	36%
Supervised Clinical Training	76%	100%	43%
Seminar/workshops	68%	100%	89%

Professional Preparation: Counseling Technique

Thirty percent of all respondents had college course work in counseling techniques, supervised clinical training, and seminar/workshop training. Thirty-seven percent of physicians, 55% of genetic counselors; and 21% of nurses had training in all three areas. Twenty-seven percent of physicians had only clinical training; 25% had clinical training and seminar/workshop training; and 13% had no training whatsoever. Twenty-seven percent of nurses had only seminar/workshop training; and 15% had no training whatsoever.

Table 4-58 Training in counseling techniques

Preparation	MD	GC	RN
Course Work in Counseling	25%	84%	38%
Supervised Clinical Training	70%	72%	42%
Seminar/workshops	45%	87%	36%

Professional Preparation: Educational Methods and Principles

Twenty-seven percent of all respondents reported no training whatsoever in educational methods and principles. Of these, 42% percent were physicians, 29% were genetic counselors, and 13% were nurses. Eleven percent of physicians, 19% of genetic counselors, and 24% of nurses completed course work in educational methods and principles, clinical training, and seminar/workshop training.

Table 4-59 Training in educational methods and principles.

Preparation	MD	GC	RN
Course Work in Ed Methods	15%	41%	47%
Supervised Clinical Training	31%	36%	39%
Seminar/workshops	41%	50%	61%

### Counseling Goals

Respondents were asked to rate the importance of six counseling goals (Table 4-60). The "important" and "not important" categories indicate what the majority say they believe.

Table 4-60 Importance of counseling goals

Important/Very Important	Not Important
Prevent disease or abnormality	Reduce the number of carriers of genetic disorders in the population
Improve the general health of the population	
Help families adjust to and cope with their disorder	
Remove or lessen the patient's guilt or anxiety	
Help individual couples achieve their parenting goals	

ANOVA found significant group differences in 4 of the 6 variables: prevent disease or abnormality; reduce the number

of carriers in the population; improve the health of the population; and help couples achieve their counseling goals.

Physicians and nurses were more likely than genetic counselors to indicate that it was important that their counseling session prevent disease or abnormality. Physicians and genetic counselors were more likely than nurses to indicate that it was not important that their counseling session reduce the number of carriers.

Nurses were more likely than physicians and genetic counselors to say it was important that their counseling improve the health of the population. Physicians were more likely than genetic counselors to say it was important that their counseling improve the health of the population.

Physicians were more likely than genetic counselors to say it was important that their counseling session help couples achieve their counseling goal. There was no significant difference between physicians and nurses and genetic counselors and nurses.

#### Educational Methods And Principles

Respondents were asked to rate the frequency with which they used 13 educational methods and principles (Table 5-2). The "always", "sometimes", "rarely", and "never" categories indicate variables that the majority of respondents say they do. The "sometimes/always" and the "rarely/never" categories had no majority.

ANOVA found significant group differences in 2 of 13 variables. Physicians and genetic counselors were more likely than nurses to do individual group counseling. Nurses were more likely than genetic counselors to ask patients to repeat what was said in their own words.

#### Factors Perceived To Increase Counseling Effectiveness

$\chi^2$  analysis found 5 of 9 significant variables: having children; personal experience with a genetic disorder; formal training in counseling techniques; formal training in educational methods and principles; and formal training in human genetics. All respondents perceived not having children as a factor that did not increase counseling effectiveness. Physicians (56%) were more likely than genetic counselors (27%) and nurses (47%) to indicate that having children was a factor that increased counseling effectiveness. Table 4-62 shows the factors that the majority of respondents perceive to increase counseling effectiveness.

Physicians (53%) were more likely than genetic counselors (28%) and nurses (42%) to indicate that having a personal experience with a genetic disorder increased counseling effectiveness. Genetic counselors (73%) were more like than physicians (30%) and nurses (42%) to indicate that formal training in counseling techniques was a factor in increasing counseling effectiveness.

The majority of physicians, genetic counselors, and nurses indicated that no formal training in educational

methods and principles was not a factor in increasing counseling effectiveness. However, genetic counselors (82%) and nurses (81%) were more likely than physicians to indicate that this was not a factor. Nurses (65%) were more likely than physicians (28%) and genetic counselors (12%) to indicate that formal training in human genetics did not increase counseling effectiveness.

Table 4-62 Factors perceived to increase counseling effectiveness.

Factors	Yes	No
Gender		X
Race/ethnicity		X
Having children		X
Not having children		X
Personal experience with a genetic disorder		X
Recognizing professional limitations	X	
Formal training in counseling techniques		X
Formal training in educa. methods and principles		X
Formal training in human genetics	X	

Table 4-61 Frequency of use of educational methods and principles

Always	Sometimes	Sometimes/Always	Rarely	Rarely/ Never	Never
Ask patients about their expectations	Assess the patient's education level	Assess the readability level of written materials	Do group counseling	Use films or videos	Use pre-tests and post-tests to assess understanding
Assess cultural beliefs of patient	Use pamphlets and/or handouts	Assess the need to see social worker			
Assess if patient is emotionally ready for information	Ask the patient to repeat what was said in his/her own words				
Prepare patient for uncertain or shocking information					
Do individual counseling					

Factors Perceived To Limit Counseling Effectiveness

$\chi^2$  analysis found 4 of 9 significant variables: race; having children; no personal experience with a genetic disorder; no formal training in human genetics. More than 90% of physicians, genetic counselors, and nurses indicated that having children and not recognizing professional limitations were not factors that limited counseling effectiveness. Table 4-63 show the factors the majority perceive to limit counseling effectiveness.

The majority of physicians, genetic counselors, and nurses indicated that race was not a factor that limited counseling effectiveness. However, nurses (95%) and

Table 4-63 Factors perceived to limit counseling effectiveness.

Factors	Yes	No
Gender		X
Race/ethnicity		X
Having children		X
Not having children		X
No personal experience with a genetic disorder		X
Not recognizing professional limitations		X
No formal training in counseling techniques		X
No formal training in educa. methods and principles		X
No formal training in human genetics		X

physicians (81%) were more likely than genetic counselors (65%) to indicate that it was not a factor. The majority of physicians, genetic counselors, and nurses indicated that being childless was not a factor that limited counseling effectiveness. However, nurses (91%) and physicians (88%) were more likely than genetic counselors (67%) to indicate that it was not a factor.

The majority of physicians, genetic counselors, and nurses indicated that no personal experience with a genetic disorder was not a factor that limited counseling effectiveness. However, nurses (91%) and physicians (86%) were more likely than genetic counselors (67%) to indicate that it was not a factor. The majority of physicians, genetic counselors, and nurses indicated that no formal training in human genetics was not a factor that limited counseling effectiveness. However, genetic counselors (97%) and physicians (89%) were more likely than nurses (77%) to indicate that it was not a factor.

#### Roles In The Counseling Process: Who Routinely Does What?

The responses given by the majority of physicians, genetic associates, and nurses are shown in Table 4-64. All physicians, genetic counselors, and nurses reported that they do not routinely refer patients to a social worker or other mental health professional.

More than 60% of physicians reported that they perform all but 2 of 27 genetic counseling-related activities: educate

patients on what to expect in the counseling session; and help families evaluate the impact of each potential outcome.

Table 4-64 Who routinely does the following genetic counseling-related activities?

Activity	MD	GC	RN
Educate the patient on what to expect in the counseling session		X	X
Construct a pedigree	X	X	X
Assess the patient's knowledge about the disorder	X		X
Assess the patient's understanding about the disorder	X	X	X
Provide accurate and complete information about the disorder	X	X	
Describe diagnostic procedures	X	X	X
Discuss the benefits and limitations of each procedure	X	X	
Obtain informed consent for diagnostic procedures	X	X	X
Call the patient at home when a diagnosis is made	X	X	
Discuss the diagnosis and prognosis with the patient	X	X	
Clarify what the physician says about the disorder	-		X
Reinforce what the physician says about the disorder	-	X	X
Identify the patient's coping strategies	X	X	X
Help the patient to identify his/her support systems	X	X	X

Table 4-64--continued

Activity	MD	GC	RN
Discuss the impact of the disorder on the family	X	X	X
Discuss the available reproductive options	X	X	
Assess the need for follow-up visits	X	X	X
Help the patient to recognize and to understand the emotional, cultural and religious factors that influence decision-making	X	X	X
Help the family hypothesize a variety of outcomes based on possible family planning decisions	X	X	X
Help the family evaluate the impact of each potential outcome on the family		X	
Ask the patient his/her preferred course of action	X	X	X
Help the client move toward the chosen course of action	X	X	X
Teach patient how to manage the disorder	X		X
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	X	X	X
Be emotionally available during crisis periods	X	X	X
Be physically available during crisis periods	X	X	X
Assess the need to see a social worker/mental health professional	X	X	X
Refer the patient to a social worker/mental health professional			
Act as a liaison between the patient and outside agencies	X	X	X
Develop patient education materials	X	X	X

All genetic counselors reported that they do not routinely clarify what the physician says about the disorder. Eighty percent or more reported that they routinely perform all but 1 of the other 28 genetic counseling-related activities: assess the patients' knowledge of the disorder.

The majority of nurses reported that they routinely perform all but 5 of the other 29 genetic counseling-related activities: provide accurate and complete information about the disorder; discuss the benefits and limitations of each procedure; discuss the diagnosis and prognosis; discuss the available reproductive options; and help families evaluate the impact of each potential outcome.

Sixty percent or more of physicians, genetic counselors, and nurses said social workers do not routinely perform any of the genetic counseling-related activities (Table 4-54).

#### Roles In The Counseling Process: Who Should Do What?

The responses given by the majority of physicians, genetic associates, and nurses are shown in Table 4-65. The majority of all respondents did not believe genetic associates should be the only health professional who should do genetic counseling.

The majority of physicians reported that they should perform all but 2 of 27 genetic counseling-related activities: educate patients on what to expect in the counseling session; and help patients identify their support systems.

Table 4-65 Who should do the following genetic counseling-related activities?

Activity	MD	GC	RN
Educate the patient on what to expect in the counseling session		X	X
Construct a pedigree	X	X	X
Assess the patient's knowledge about the disorder	X	X	X
Assess the patient's understanding about the disorder	X	X	X
Provide accurate and complete information about the disorder	X	X	
Describe diagnostic procedures	X	X	X
Discuss the benefits and limitations of each procedure	X	X	
Obtain informed consent for diagnostic procedures	X	X	X
Call the patient at home when a diagnosis is made	X	X	
Discuss the diagnosis and prognosis with the patient	X	X	
Clarify what the physician says about the disorder	-	X	X
Reinforce what the physician says about the disorder	-	X	X
Identify the patient's coping strategies	X	X	X
Help the patient to identify his/her support systems		X	X

Table 4-65--continued

Activity	MD	GC	RN
Discuss the impact of the disorder on the family	X	X	X
Discuss the available reproductive options	X	X	X
Assess the need for follow-up visits	X	X	X
Help the patient to recognize and to understand the emotional, cultural and religious factors that influence decision-making	X	X	X
Help the family hypothesize a variety of outcomes based on possible family planning decisions	X	X	X
Help the family evaluate the impact of each potential outcome on the family	X	X	X
Ask the patient his/her preferred course of action	X	X	X
Help the client move toward the chosen course of action	X	X	X
Teach patient how to manage the disorder	X	X	X
Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed	X	X	X
Be emotionally available during crisis periods	X	X	X
Be physically available during crisis periods	X	X	X
Assess the need to see a social worker/mental health professional	X	X	X
Refer the patient to a social worker/mental health professional	X	X	X
Act as a liaison between the patient and outside agencies	X	X	X
Develop patient education materials	X	X	

More than 65% of genetic counselors reported that they should perform all 30 genetic counseling-related activities. The majority of nurses indicated that they should perform all but 5 of the 30 genetic counseling-related factors: providing accurate and complete information about the disorder; discussing the benefits and limitation of each procedure; calling patients at home when a diagnosis is made; discussing the diagnosis and prognosis; and developing patient education materials.

The majority of physicians, genetic counselors and nurses indicated that social workers should not perform any of the 30 genetic counseling-related activities.

CHAPTER 5  
DISCUSSION AND IMPLICATIONS

This study was part of a project conducted under the aegis of the Morehouse School of Medicine in Atlanta, Georgia and the University of Florida College of Medicine in Gainesville, Florida. The project, "The Impact of Human Genome Initiative Derived Technologies on Genetic Testing, Screening and Counseling: Social, Ethical and Legal Issues" was funded by the Department of Energy (DOE) and the National Institutes of Health (NIH).

As part of the project, the current study sought to answer the following questions:

1. What are the qualifications and training of professionals in the southeastern United States who provide genetic counseling?
2. What are the current roles (i.e. functions, duties, and contributions) of nurses, genetic associates, and physicians in the genetic counseling process.
3. What are the perceptions of nurses, genetic associates, and physicians regarding what their roles (i.e. functions, duties, and contributions) should be in the genetic counseling process?

4. What are the educational methods used by these health professionals in genetic counseling?

The study consisted of a mail survey of persons who do genetic counseling in the southeastern United States (Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee).

#### Demographics

In the present study, genetic counseling in the Southeastern United States is provided primarily by whites (91%) and by women (70%). Rapp (1988) reported that of the more than 600 genetic counselors/associates practicing in the 1980s, 99% were white and greater than 95% were women. In the present study, 91% of genetic associates were women; 72% of physicians were men.

Duster (1990) believe that if genetic counselors come from a very different social and cultural background than their clients, there is a high potential for role conflict and the counseling session will "be fraught with landmines of interethnic, interracial, interclass, intergenerational misunderstandings" (p. 80). Genetic disorders are unevenly distributed through class, racial, and ethnic grouping, and genetic counseling is very much a part of the social and political relationship of the era (Duster, 1990). Rapp (1988) demonstrates this point in an analysis of how "informed consent" takes on different shapes and meaning, depending on

the class positions of the doctor-patient or counselor-client relationships.

### Education

Health professionals who provide genetic counseling services in this study have similar diverse educational credentials and background experiences to their national counterparts (Kelley, 1986; National Society of Genetic Counselors, 1990). These professionals include genetic associates (32%), physicians (30%), nurses (23%), social workers (3%), lab directors, and various other persons with assorted doctoral, master's, bachelor's, and associate degrees.

### Patient Population

Physicians (45%) genetic counselors (49%), and nurses (51%) describe their patient population as a mixture of pediatrics and prenatal. Sorenson et al. (1981), reported that clinical geneticists worked mainly with pediatric patients. This occurs because genetics has not thus far been integrated into medicine as a preventive activity, "but through work with children born with birth defects" (Sorenson et al; 1981, p. 39). In this study, however, only 25% of physicians and 23% of nurses work only with pediatric population; while 37% percent of genetic associates work only with a prenatal population.

### Facility

This study, like Sorenson et al. (1981), found genetic counselors working in a variety of settings, with most (61%) located in medical centers. This is because genetic counseling is not a primary but a tertiary care service, requiring highly trained subspecialties and technologies mostly found at medical centers (Harris, 1989; Sorenson et al, 1981). In this study, 67% of genetic associates worked at university medical centers. The number of genetic associates per facility varied from 1 to 7; 48% of the facilities had 3; and 24% had 1.

The majority of facilities in this study were located in urban areas. This usually requires clients to travel long distances (Harris, 1989; Sorenson et al. 1981). The Florida/Georgia human genome project found that in Florida, the three regional genetic centers were located at university medical centers (the University of Florida, Gainesville, Florida; the University of Miami, Miami Florida, and the University of South Florida, Tampa Florida). Clients throughout Florida have to travel to one of these centers. Genetic associates from these centers provide routine follow-up visits at rural satellite clinics.

In Georgia, community health nurses, trained in genetic counseling, provide genetic services (including home visits) to rural areas (Harris, 1989). Some practitioners feel that it is not feasible for rural centers to ask individuals to

travel distances as far as 350 miles to urban centers for counseling or cost effective to send a counselor a similar distance to see two or three patients (Cadle & Biesecker, 1987; Getting et al., 1987; Harris, 1989).

Sorenson et al. (1981) found very few genetic services provided at public health agencies. The majority of nurses in this study worked at public health departments. Nurses deliver more community and maternal child health services than any other group (Schmerler & DeConstanzo, 1992). In rural and satellite clinics, genetic associates may be regarded as outsiders and local nurses can provide invaluable services such as referrals and creating an attitude of trust (Cadle & Biesecker, 1987; Gettig et al., 1987). It is possible that the public health nurses in this study do initial screening and assessments and refer clients to medical centers for further evaluation and diagnosis.

### Experience, Preparation And Training

#### Experience

This study, like Sorenson et al. (1981), found MD and PhD degree counselors had at least 6 more years of experience than master's trained genetic associates. Social workers in this study also practiced longer than master's trained genetic associates while nurses and master's trained genetic associates had comparable years of experience. Genetic associates have less counseling experience than other professionals because of the recent development and growth of

genetics in medicine (Sorenson et al., 1981). Until the early 1970s, physicians with an interest in genetics or PhD geneticists with an interest in medicine were the professionals who almost exclusively provided genetic counseling (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). In the 1970s, genetic associates with master's degrees emerged in response to a substantial increase in demand for screening and counseling.

Master's trained genetic associates are the health professionals specifically trained to do genetic counseling (Rollnick, 1984). Training programs for these professionals developed when it was found that genetic associates could successfully provide many of the genetic services--history, pedigree construction and analysis, literature review, counseling, education, and referral--once supplied by physicians (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983; Rollnick, 1984).

#### Human Genetics

Unlike Sorenson et al. (1981), this study did not find comparable levels of course work and clinical training in human genetics. Among professionals, genetic associates in this study had more course work and clinical training in human genetics than physicians, social workers, and nurses. All genetic associates had clinical training in human genetics

compared to physicians (76%), social workers (57%), and nurses (43%). Genetic associates, social workers, and nurses were more likely to have seminar/workshop training in human genetics than physicians.

It appears that physicians rely more on supervised clinical training and seminar/workshop training than course work for knowledge on human genetics. Human genetics is not uniformly taught in medical schools. A report cited by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research (1983) found that 30% of the 104 medical schools surveyed offered no formal course in human genetics. Those that provided training had varying emphasis on the subject. Childs (1993) reports that more schools are devoting more hours to genetics; but at John's Hopkins, for example, the number of hours of genetics has declined rather than increased. Childs furthermore believes that there is no need to add anything to the medical curriculum. Instead, he sees a need to change the emphasis from memorizing to understanding information within the context of the patients' lives.

This study suggests that genetic counselors rely equally on course work, supervised clinical training, and seminar/workshop training for knowledge on human genetics. As part of this project, curriculum information was requested from programs that train board eligible genetic counselors. Sixteen of the 21 programs in the United States sent the

requested information (Appendix 4). Two of these programs had a genetic counseling tract for nurses enrolled in graduate nursing programs; one program trained individuals with M.S. or PhD degrees in other fields; and the remaining 13 programs trained master's level genetic associates. While the curricula vary, all include courses in human genetics, medical genetics, counseling skills, and supervised clinical internships. These programs seemingly provide counselors with a sound foundation of knowledge about genetic disorders, how they are diagnosed, how they are transmitted, and the clinical implications of specific disorders (Marks, 1984). Graduates are eligible for certification from the American Board of Medical Genetics (Rapp, 1988).

It appears that nurses rely primarily on seminar/workshop training for knowledge on human genetics. Course work in human genetics is usually absent from the nursing curriculum, and information on genetics is only sporadically offered in nursing education (Feetham, 1984). Mertens et al. (1984) reported that 96.5% of nurses had less than 10 hours of genetics in their curriculum; and 70% of nursing instructors never had a college-level genetics course. Feetham (1984) suggests that any deficient needs in the nursing curriculum can be met through continuing education, supervised clinical experiences, and didactic content in degree programs at the graduate or undergraduate level. Curriculum information from two graduate nursing programs with genetic counseling tracts

was sent to this investigator. They showed required college course work in the basic principles of molecular and human genetics, college work in counseling techniques, and supervised clinical training in human genetics.

Social workers also appear to rely primarily on seminar/workshop training for knowledge on human genetics. Since courses in human genetics are not part of the social work curriculum, Bishop (1984) recommends: 1) all graduate social workers have a working knowledge of genetic diseases, their etiology, and their consequences; 2) graduate schools of social work develop core curriculum and field practice experience in human genetics; and 3) continuing education areas in genetics be offered regularly.

#### Counseling Techniques

Like Sorenson et al. (1981), this study found a small percentage of physicians and nurses with formal course work in counseling techniques compared to genetic counselors. Unlike Sorenson et al., however, this study did not find that genetic associates had considerable more supervised clinical training in counseling techniques than physicians. Genetic associates in this study had more seminar/workshop training in counseling techniques than physicians and nurses.

These data suggest that physicians rely primarily upon supervised clinical experiences in developing counseling skills and techniques and less on formal course work. In order to maximize their effectiveness as genetic counselors,

Davis (1984) suggests that MD geneticists obtain a full psychosocial history to gain appropriate insights into the prospective counselee's expectations, emotional state, cultural beliefs, level of education, economic status, and family structure.

Genetic associates, on the other hand, appear to rely on all forms of training to develop their counseling skills and techniques. Curriculum information from genetic counseling programs showed required course work in counseling techniques, psychosocial aspects of counseling, and supervised clinical training.

It appears that nurses have little training in counseling techniques. They rely slightly more on seminar/workshop training than course work and clinical training to develop genetic counseling skills and techniques. However, Feetham (1984) notes that most nursing education does include content and practice emphasis on the psychosocial/counseling aspect of care.

All social workers in this study had course work, clinical training, and seminar/workshop training in counseling techniques. Social workers have extensive training on the psychosocial aspects of counseling, crisis intervention, and bereavement counseling (Rauch, 1988).

#### Educational Methods And Principles

The majority of physicians, genetic associates, and nurses did not have course work nor supervised training in

educational methods and principles. The majority of nurses had seminar/workshop training in educational methods and principles. Nurses consistently had more course work, and seminar/workshop training in educational methods and principles than all other genetic counseling professionals. As with training in human genetics, and counseling techniques, it appears that nurses rely primarily on seminar/workshop training to develop patient educational skills. Genetic associates, physicians, and social workers also rely primarily on seminar/workshop training to develop patient education skills.

None of the genetic program curriculum sent to the investigator showed required or recommended courses in educational methods and principles.

#### Work Week

The number of hours spent on genetic counseling vary by health professional. Sorenson et al. (1981) reported that: 1) on average clinics schedule about 10 hours/week for genetic counseling; 2) genetic associates spent 30 hours/week (80% of their time) on genetic counseling; and 3) physician spend 17 hours/week on genetic counseling. As expected genetic associates in this study, spend more time doing genetic counseling than physicians and nurses. Unlike those in the Sorenson et al. study, only 28% of genetic counselors spend 20 or more hours/week on genetic counseling; 49% spend 11 to 20 hours/week on genetic counseling. The majority of physicians

and nurses spend less than 10 hours/week on genetic counseling.

The number of hours spent on clerical/administrative tasks also vary by health professional. Genetic counselors spend significantly more time on clerical/administrative tasks than physicians and nurses. The majority of genetic counselors spend more than 11 hours/week; the majority of physicians spend less than 5 hours/week; nurses equally spend less than 5 hours/week and more than 11 hours/week on clerical/administrative tasks.

The majority of all physicians, genetic associates, and nurses are not involved in any genetic support groups and spend less than 5 hours/week on community education activities.

This study supports finding by Sorenson et al. (1981) that show genetic counseling is not a full time activity for most physicians. Genetic counseling also does not appear to be a full time activity for the genetic associates and nurses in this study. The average length of the genetic counseling session for all health professionals is 30 to 60 minutes, compared to 60 minutes found by Sorenson et al. The majority of physicians and nurses saw less than 9 persons/week for genetic counseling; 42% of genetic associates saw less than 9 persons/week. Only 38% of physicians and 28% of genetic associates saw 10 to 20 persons/week for genetic counseling. Since most of these health professionals work in tertiary

medical centers, they are also probably engaged in research, teaching, clinical services, and other activities. Also, those who travel to satellite clinics probably spend a considerable amount of their time traveling.

#### Counseling Goals

Respondents were asked to rate the importance of six counseling goals: prevent disease or abnormality; reduce the number of carriers of genetic disorders in the population; improve the general health of the population; help families adjust to and cope with their genetic disorders; remove or lessen the patient's guilt or anxiety; and help individual couples achieve their parenting goals.

Unlike the findings by Sorenson et al., the majority of respondents in this study did not support the population-focused goal to reduce the number of carriers of genetic disorders in the population. Kelley (1986) views the purpose of genetic counseling as the maximal use of medical technology to reduce the incidence of genetic disorders, and hence, the financial impact on society. Physicians and genetic associates were more likely than nurses to say that this goal was not important.

Like the findings by Sorenson et al., the majority of respondents said it was important or very important that their counseling achieve the other five goals. The positive support for preventing disease or abnormality and improving the general health of the population indicate societal or

population-focused goals, either at the disease or genetic level (Shaw, cited in Lubs & de la Cruz; 1977; Sorenson et al., 1981, p. 42).

The ninety percent or more support for the other three goals indicate beliefs in the educative aspect of genetic counseling and protection of individual autonomy by encouraging counselees to make their own reproductive decisions (Shaw, cited in Lubs & de la Cruz, 1977; Sorenson et al., 1981).

Data from this study suggest that genetic counselors share the philosophical perspectives of health education and of public health that: 1) health is a personal and societal issue; and 2) the critical outcome of a health education intervention is that the client possesses the understanding, skills, and experience needed to make and implement informed health decisions (AAHE, 1992; Shireffs, 1984; Bates & Winder, 1984). Genetic counseling and health education also face the challenge of maintaining the individual's freedom while achieving desirable social ends (Bates & Winder, 1984). However, unlike health education, modern genetic counseling, does not attempt to: 1) change individual and group behavior; 2) bring about some shift in belief or attitude; 3) effect changes in behavior or lifestyle; 4) ask clients to alter their lifestyles for the larger "public good"; and 5) persuade clients to pursue a specific course of action, i.e., they are nondirective (Bates & Winder, 1984; Kessler, 1992b; Sorenson,

1981; Tones, 1990). Though health educators are openly directive in their approach, Kessler (1992b) suggests that genetic associates can be directive in more subtle ways:

. . . in providing genetic education, the counselor simultaneously may transmit direct and indirect attitudes, suggestions, value judgements, preferences, and directives simply by spending more time on one option rather than another or by expending slightly greater energy and enthusiasm on option A rather than option B. Just by focusing the counselee's attention on potential risks, genetic and otherwise, and/or on the consequences of genetic diseases the counselor communicates more than objective, neutral information. (Kessler, 1992b, p. 10)

#### Educational Methods And Principles

Imparting information and understanding what that information means to clients is an integral aspect of genetic counseling (Sorenson 1981; Kelly, 1986). Therefore, genetic counseling can be viewed as a form of health education, and the philosophical and theoretical issues which affect health education also affect genetic counseling. The critical outcome of a health education intervention is that the client possesses the understanding, skills, and experience needed to make and implement informed health decisions (Shireffs, 1984).

Respondents were asked to rate the frequency with which they used 13 educational methods and principles (Table 4-61). There were no significant differences between health professionals on 4 of the 5 variables that were reportedly always used.

Planned patient education programs and services include activities designed to inform patients about their medical condition and to assist patients to manage their disease and to modify their behavior in order to promote health and prevent disease (Squyres, 1985). If educational methods such as those in the "sometimes" and "never" categories are not always used, the effectiveness of the counseling session is compromised. If the patient's educational level is not appropriately assessed at all times, then the counseling session cannot be tailored to the client's need. Also, pamphlets and booklets (if used) may be too technical for some patients. Counselors should not automatically assume that well-educated clients will have little or no problem understanding the information (Sorenson et al., 1981). If information is not presented in a way that clients can understand then the client's ability to make an informed decision is questionable.

Clients are not always asked to repeat what the counselor said in their own words and are never pre-tested and post-tested to assess their understanding. If these are not always done then the counselor has no idea what information to add, repeat, emphasize, or clarify. Asking clients to repeat information is a "test of learning and provide an opportunity to correct learning or correct misinformation" (Sorenson et al., 1981, p. 137).

Sorenson et al. (1981) also conclude that despite their different educational backgrounds, health professionals (MDs, PhDs, and master's level genetic associates) who do genetic counseling are equally effective (or ineffective) as educators. They suggest that more attention should be given to client education issues and techniques for improving learning in the training of these professionals. In the study by Sorenson et al. (1981), many of the clients' genetic-medical and sociomedical concerns were never addressed by the genetic counselors in the counseling session. They concluded that genetic associates are not making significant or only small differences in terms of client information; and genetic counseling as an educative activity is only moderately effective, with much room for improvement. However, this study indicates that these recommendations are not being implemented.

#### Counseling Effectiveness

Respondents were asked to indicate which of nine factors, if any, increase or limit their counseling effectiveness (Tables 4-62 and 4-63). Responses for the majority are given.

Recognizing professional limitations and formal training in human genetics are the only factors perceived to increase counseling effectiveness by the majority of all respondents. Responses to 5 of the 9 variables depended on the health professional.

The majority of nurses do not consider formal training in human genetics as a factor that increases counseling effectiveness. Providing correct information about the diagnosis, prognosis, and the disorder itself is the primary goal of genetic counseling (Kessler, 1992a). These nurses rely primarily on seminar/workshop training for knowledge on human genetics. Seminars/workshops may not provide many of the core information needed on human genetics. Though the majority of nurses also agree that formal training in educational methods and principles does not increase counseling effectiveness, they disagree at least 20% less than physicians and genetic counselors.

The majority of all respondents do not consider any of the variables as factors that limit counseling effectiveness. However, responses to 4 of the 9 variables depended on the health professional.

These data suggest that 7 of the 9 variables are perceived to neither increase nor limit counseling effectiveness (i.e. they are considered neutral). Duster (1990) contends that the race of the counselor plays a large factor in the counseling process. As the American population become more diverse, genetic counselors will have to deal with families from a wider social and cultural spectrum. In the area of sickle-cell anemia education and counseling, many jobs are located in black communities. In these agencies, there usually is "unstated tension and disagreement about the degree

of importance attached to the race of counselors, i.e., whether or not these counselors should be black" (Duster, 1990, p. 82). Duster believes that the Tuskegee Syphilis Study has many implications for the discussion and selection of genetic counselors. He states:

. . . only when a society is relatively homogeneous with respect to racial and ethnic distinctions, and to privilege, can technical competence be the "neutral" first principle. . . Technical expertise is only one element involved in health counseling. A second element, certainly equal in importance, is the social and political relationships that provide the context in which counselor and counselee communicate. (Duster, 1990, p. 85)

Surprisingly, the majority of respondents said personal experience with a genetic disorder does not increase and does not limit their counseling effectiveness. Kessler (1992c) reports that when counselors experience the same or similar disorder as their clients, it affects them as individuals and changes the character of their work. In addition, counselors become either patient or impatient with the clients and struggle to contain their feelings (associations and projections).

In this study, male physicians were part of the genetic counseling teams more often than any other health professionals. Yet the majority of respondents did not believe gender to be a factor that increases or limits counseling effectiveness. However, other researchers (Kessler, 1992a; Zare et al. 1988) have found gender of the

counselor to be a factor which influences counseling the effectiveness.

Zare et al. (1988) reported that male counselors spent more time than female counselors discussing topics other than the core counseling issues. The researchers concluded that the lack of discussion of significant issues increases the likelihood that patient reproductive decisions will be based on less information than is available. Female counselors are more likely to report clearer explanations of risk, etiology, and prognosis than male counselors (Kessler, 1992a). Also, female clients asked about their concerns more frequently when the counselor was female than when the counselor was male (Kessler, 1992a). The process of medical education, as well as subsequent training, contribute to the acquisition of attitudes that may condition male providers to be more reserved and less involved with women patients than female providers (Zare, 1988).

#### Genetic Counseling

Respondents were asked to indicate which professional in their facility routinely does and should do 30 genetic counseling-related activities. The responses given by the majority of physicians, genetic associates, and nurses are shown in Tables 4-64 and 4-65.

In a survey of 205 genetic counselors in 25 states and the District of Columbia, Sorenson et al. (1981) found genetic counseling was done primarily by physicians (66%, including

PhDs) and master's trained genetic associates (19%). In the present study of 204 health professionals in nine states, 31% were genetic associates (8% with PhDs); 30% were physicians, and 22% were nurses.

These data do not support Sorenson's conclusion that genetic counseling is an activity practiced mainly by medically trained professionals. Sorenson's study was more than a decade ago, and these differences may be due to an increase in team approach to genetic counseling; and an increase of certified genetic associates (National Society of Genetic Counselors, Inc., 1990). It also is highly likely that more physicians now refer patients to certified genetic associates; and there has been an increase of clinical nurse specialists trained in genetic counseling.

Like Sorenson et al. (1981), this study found genetic counseling was usually a team effort, consisting mostly of physicians and relatively few social workers. Physicians were part of the team 80% of the time and social workers were part of the team only 9% of the time.

Surprisingly, the majority of physicians do not do and do not think that they should educate patients on what to expect in the counseling session. The agendas of the client and counselors are usually discordant and counselors are usually too wedged to their own agendas so that sufficient time is not available to address the client's concerns (Kessler, 1992a; Sorenson, 1992). As the dominant professionals in genetic

counseling, physicians "determine the form, flavor, and eventually the effectiveness of genetic counseling" (Sorenson et al., 1981, p. 33).

Like Sorenson et al. (1981), this study found that genetic associates rarely operated independently and the team consisted usually of physicians and genetic associates. Although they are specifically trained to be genetic counselors, genetic associates, with or without PhDs, rarely operate independently because they lack the diagnostic skills that would allow them to be autonomous counselors (Sorenson et al., 1981).

Unlike Sorenson et al. (1981), this study found nurses play a large part in the genetic counseling process. The nurse's role in genetic counseling usually includes: 1) screening; 2) assessing physical and psychosocial responses; 3) referring to supportive services; 4) providing direct care; 5) diet counseling; and 6) teaching the child, family, and other health professionals (Feetham, 1984).

The majority of physicians, genetic associates, and nurses said social workers do not and should not routinely perform any of the 30 genetic counseling-related activities. All these health professionals routinely performed tasks that would be considered within the realm of the social worker. In addition, 100% of all these health professionals said they do not usually refer patients to see a social worker or other mental health professional. However, the majority realized

that they should be doing so. Duster (1990) questions the ability of genetic counselors to adequately deal with many of the psychosocial issues that are raised during counseling. He states:

. . . it is one thing to know about the devices for dealing with momentary displays of disturbance. It is another to try to attend to the "chronic" structural features that may be the source of that upset, and to offer good counsel about the long-term consequences of having a child with a debilitating disorder. (Duster, 1990, p. 80)

Most genetic counseling tends to consist of educating clients about hereditary mechanisms, discussing etiology and recurrence risks, and providing other factual information, with minimal time spent on psychosocial issues (Kessler, 1992a).

The underutilized services of social workers may not be in the patients' best interests. Great differences exist between people in their capacities to deal with and live with genetic disorders (Duster, 1990). Along with the disorder, many patients must often deal with the problems of poverty and racism (Hernandez, 1989).

When social workers are part of the genetic team, they focus on the psychosocial aspect of counseling, assess social service needs, make appropriate referrals, act as case managers, and offer crisis intervention during exacerbation of disorders and during bereavement (Rauch, 1988). The role of social worker as cultural mediator is also important because "the ethnic influences that motivate clients often need to be

interpreted to others to ensure appropriate treatment (Fandetti & Goldmeier, 1988).

The majority of respondents realize that genetic associates should not be the sole providers of genetic counseling. No single individual can provide appropriate genetic counseling in all, or even most, situations (Kelley, 1986). People vary with respect to class, culture, and heritages, so there can be no singular path of confidence and competence for genetic counselors (Duster, 1990). Also no single formula or professional guidelines can adequately define the correct role of the genetic counselors (Duster, 1990).

The multidisciplinary genetics team may include clinical geneticists, pediatricians, obstetricians, neonatologists, genetic associates, social workers, and nurses (Kelley, 1986; National Society of Genetic Counselors, Inc., 1991; Sorenson, 1981). Though some overlapping of roles occur, each discipline offers a different clinical perspective and provides different insights to the counseling process (Davis, 1984). If a team approach is used, then the team members' roles should be clearly delineated from the start (Davis, 1984).

Chin and Falk (1990) provide four advantages to a team approach to genetic counseling:

1. It provides a comprehensive approach to diagnosis and treatment.

2. It is convenient for the family and is less disruptive of the family's work and other routine.
3. It facilitates communication among the team members, decreases duplication of services, and increase efficiency or care and implementation of services.
4. It increases the quality of care provided to patients.

#### Conclusions

The findings in this study must be considered preliminary. It is possible that a larger sample and a more sensitive instrument may have detected more significant findings.

With the aid of new technologies, prospective parents can discover if their fetus will be affected with a genetic disorder. Recent advances in medical genetics have resulted in a demand for more and better genetic counseling services. These advances have included increased knowledge about how certain diseases are inherited, the ability to detect chromosomal abnormalities, and prenatal diagnosis of certain diseases.

Though the technology exists for detecting some genetic disorders, much information about the human genome remains to be discovered. The Human Genome Project is a coordinated research endeavor, jointly sponsored by the National Institutes of Health and the Department of Energy. The 15-year projects aims to: 1) acquire complete knowledge of the

organization, structure, and function of the human genome; 2) map and sequence the 3 billion base pairs that make up the human genome; and 3) to construct common resources for the study of human genetics. As technology advances through spinoffs of research sponsored by the Human Genome Initiative/Human Genome Project (HGI) and other genome research, less expensive and more accurate tests for diseases will be readily available.

Genetic counseling is the current health service approach to educating about and possibly preventing many genetic diseases. Genetic counseling is usually done by a team of health professionals which includes physicians, genetic associates, and nurses. The majority of respondents do not believe genetic associates should be the only health professionals doing genetic counseling.

There are overlapping roles in the counseling process and considerable disagreement over which professional should be responsible for particular genetic counseling-related activities. Physicians and genetic associates especially differed with nurses on the roles of nurses in genetic counseling. Social workers are not usually part of the counseling team and clients are not routinely referred to them.

Genetic counseling is usually done at university medical centers located in urban areas. Counselors usually work with a mixture of pediatric and prenatal patients, prenatal

patients, and pediatric. Genetic counseling is not a full time activity for the majority of respondents.

Genetic counselors have diverse educational credentials and clinical experiences. As the health professional specifically trained to do genetic counseling, genetic associates tend to be well trained in human genetics and counseling techniques, but like physicians and nurses lack preparation in the educative aspect of counseling. Physicians have more years of experience doing genetic counseling than genetic associates and nurses, but the bulk of their training apparently derives from supervised clinical training rather than formal courses in human genetics, counseling techniques, and educational methods and principles. Nurses have equal length of genetic counseling as genetic associates but lack the formal courses in human genetics and counseling techniques. The effectiveness of each of these groups as genetic counselors was not assessed in this study but warrants further investigation.

One of the predicted ramifications of the Human Genome Project is an unprecedented increase in genetic information. Medical practitioners and certified genetic counselors will not be able to keep current in this voluminous field of information. In addition, the shortage of certified genetic counselors will continue in the foreseeable future. Special continuing education programs or academic tracts for other health professionals such as nurses and certified health

education specialists will need to be developed to provide appropriate genetic education and counseling programs for the American population. A sociodemographic and ethnically diverse pool of students must be recruited into these programs.

#### Policy Recommendations

1. Medical, nursing, and social work schools should offer an option for formal course work in human genetics. Schools that currently offer such classes should evaluate and upgrade their course content for information regarding the medical and non-medical implications of genetic testing and screening.
2. Training should enable counselors to provide genetic counseling that meets or exceeds standards set by the American College of Medical Genetics. The session should include information on the diagnosis and prognosis of the disorder, the benefits and limitations of each diagnostic procedure, the type of information that will be derived, the significance of positive or negative tests, and the ways in which results will be used.
3. Professional societies such as the American Medical Association, the American Nurses Association, the National Association of Social Workers, Inc., and the National Society of Genetic Counselors, Inc. should offer continuing education course/workshops in human genetics; counseling techniques; client-centered learning; psychosocial aspects of genetic counseling; the historical and contemporary implications of

genetic testing, screening, and counseling; and race/ethnic issues in genetic testing, screening, and counseling.

4. Graduate schools of social work and nursing should develop core curriculum and field practice experience in human genetics. Graduate social work and nursing students majoring in maternal and child health should be required to complete the core curriculum in human genetics.

5. Efforts must be systematically taken to increase and improve the counseling aspects of genetic counseling. Supervised clinical training alone (especially for physicians and nurses) is inadequate for teaching the substantive content or techniques needed for effective counseling of sociomedical topics. Also senior professionals may not always be the best role models since experience may not be an indicator of counseling effectiveness.

6. The need to see a social worker or other mental health professional should be assessed at every counseling session. Counselors should be taught to recognize counseling issues beyond their scope of knowledge.

7. Since social workers have extensive training on the psychosocial aspects of counseling, crisis intervention, and bereavement counseling, they should be a part of every genetic counseling team. If not part of the genetic counseling team then clients should routinely be referred to a social worker or other mental health professional.

8. If a team approach to counseling is used, the roles of each team members should be clearly delineated.

9. In facilities where counseling is essentially a one-person operation, effort should be made to utilize other community resources such as social service agencies, mental health centers, support groups, etc.

10. Genetic counseling as an educative activity should be made more substantive. Counselors must understand, utilize, and integrate educative methods. The client's knowledge of risk and diagnosis should routinely be ascertained at the beginning and end of each counseling session. This would provide an opportunity to reinforce learning and correct misinformation, which is conducive for maximum learning.

In the training of each of these different health professionals, more attention needs to be given to client education and techniques to improve client learning. Even though some professionals reported seminar workshop training in educational methods and principles, they need to be taught how to translate these into practice.

11. The client's education level, cultural beliefs, and support systems should be identified and assessed at the beginning of each counseling session. This allows the counseling session to be tailor made to the client's specific needs and agenda rather than be dominated solely by the counselor's agenda.

12. The sociodemographic and ethnic composition of the pool of genetic associates needs to be increased. Minority students should be aggressively recruited in to genetics training program. These programs also should sensitize male students to counseling a predominantly female population.

13. Special continuing education programs or academic tracts for other health professionals such as nurses and certified health education specialists will need to be developed to provide appropriate genetic education and counseling programs for the American population.

## GLOSSARY

Anomaly	Congenital malformation, such as the absence of a limb (Mosby's Medical & Allied Health Dictionary, 1990).
Amniocentesis	An obstetric procedure in which a small amount of amniotic fluid is removed to aid in the diagnosis of fetal abnormalities. This is usually performed at 15-18 weeks of pregnancy, but can be performed as early as 12-weeks (Mosby's Medical & Allied Health Dictionary, 1990).
Autosome	Any chromosome that is not a sex-linked chromosome. Humans have 22 pairs of autosomes, which are involved in transmitting all genetic trait and conditions other than those that are sex-linked (Mosby's Medical & Allied Health Dictionary, 1990).
Certified Genetic Counselor	A master's trained genetic counselor who is certified by the American Board of Medical Genetics.
Chorionic Villus Sampling	An obstetric procedure in which tissues from the chorionic villi is removed to aid in the diagnosis of fetal abnormalities. This is usually performed at 9-11 weeks of pregnancy (The Merck Manual, 1990).
Chromosome	Any one of the thread-like structures in the nucleus of a cell that function in the transmission of genetic information (Mosby's Medical & Allied Health Dictionary, 1990).
Congenital Anomaly	Any abnormality present at birth which may be inherited genetically (Mosby's Medical & Allied Health Dictionary, 1990).

Consanguinity	A hereditary or "blood" relationship between persons, by having a common parent or ancestors (Mosby's Medical & Allied Health Dictionary, 1990).
Counselee	The person who is the recipient or target of genetic counseling; also referred to as the client or the patient (Kelley, 1986).
Cytogenetics	The branch of genetics that studies the cellular constituents concerned with heredity, primarily the structure, function, and origin of the chromosome (Mosby's Medical & Allied Health Dictionary, 1990).
Directive Counseling	Counseling in which individuals are directed to a preconceived limitation on the options from which they might chose. Recommendations and advice are given (Kelley, 1986).
Dominant Gene	A gene that expresses its effect even when it is present on only one chromosome (The Merck Manual, 1990).
Dominant Trait	An inherited characteristic, such as eye color, that is likely to appear in an offspring although it may occur in only one parent (Mosby's Medical & Allied Health Dictionary, 1990).
Eugenics	The study of methods for controlling the characteristics of future human populations through selective breeding (Mosby's Medical & Allied Health Dictionary, 1990).
Gene	The biologic unit of genetic material and inheritance (Mosby's Medical & Allied Health Dictionary, 1990).
Genome	The complete set of genes in the chromosomes of a particular organism (Mosby's Medical & Allied Health Dictionary, 1990).

Genetic Associate	A master's trained genetic counselor who is certified by the American Board of Medical Genetics.
Genetic Counseling	An educational process that seeks to assist affected and/or at risk individuals to understand the nature of the genetic disorder, its transmission and the options available to them in management and family planning (Kelley, 1986).
Genetic Counselor	A health professional who provides genetic counseling.
Genome	The complete set of genes in the chromosomes of each cell (Mosby's Medical & Allied Health Dictionary, 1990).
Health Education	Any combination of learning experiences designed to facilitate voluntary actions conducive to health (Green and Kreuter, 1990).
Health Promotion	Any combination of educational, organizational, economical, and environmental supports for behavior conducive to health (Green and Kreuter, 1990).
Nondirective Counseling	Counseling in which individuals are free to make their own decisions based on understanding of the risks and options that they face (Kelley, 1986).
Recessive Gene	The members of a pair of genes that lacks the ability to express itself in the presence of its more dominant alleles (Mosby's Medical & Allied Health Dictionary, 1990).
Recessive Trait	A genetically determined characteristic that is expressed only when present in the homozygotic state (Mosby's Medical & Allied Health Dictionary, 1990).

APPENDIX 1  
INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

UNIVERSITY OF FLORIDA  
INSTITUTIONAL REVIEW BOARD  
114 PSYCHOLOGY BUILDING  
GAINESVILLE, FL 32611-2065  
(904) - 392 - 0433

October 16, 1992

TO: Ms. Delores C. Arnotrading  
5 FLG

FROM: C. Michael Levy, Chair, *CML*  
University of Florida Institutional  
Review Board

SUBJECT: Approval of Project # 92.304  
Assessment of educational methods used by genetic counselors  
in the Southeastern United States

I am pleased to advise you that the University of Florida Institutional Review Board has recommended the approval of this project. The Board concluded that your subjects will not be placed at risk in this research, and that it is not essential that you obtain legally effective (signed, witnessed) informed consent from each participant.

If you wish to make any changes in this protocol, you must disclose your plans before you implement them so that the Board can assess their impact on your project. In addition, you must report to the Board any unexpected complications arising from the project which affect your subjects.

If you have not completed this project by October 16, 1993, please telephone our office (392-0433) and we will tell you how to obtain a renewal.

By a copy of this memorandum, your Chair is reminded of the importance of being fully informed about the status of all projects involving human subjects in your department, and for reviewing these projects as often as necessary to insure that each project is being conducted in the manner approved by this memorandum.

CML/her

cc: Vice President for Research                      Unfunded  
College Dean  
R. M. Pigg  
Dr. Barbara Rienzo

APPENDIX 2  
QUESTIONNAIRE

APPENDIX 1  
QUESTIONNAIRE

- Q-1 Which of the following best describes your facility?  
(circle the number)
- 1 UNIVERSITY MEDICAL CENTER
  - 2 PUBLIC HOSPITAL
  - 3 PUBLIC HEALTH DEPARTMENT
  - 4 PRIVATE/GROUP PRACTICE
  - 5 COMMERCIAL GENETICS LABORATORY
  - 6 OTHER (specify)\_\_\_\_\_
- Q-2 Which of the following best describes your patient population?  
(circle the number)
- 1 PEDIATRIC
  - 2 PRENATAL
  - 3 MIXTURE OF PRENATAL AND PEDIATRIC
  - 4 GENERAL POPULATION
- Q-3 Circle the area where your facility is located?
- 1 URBAN
  - 2 RURAL
  - 3 SUBURBAN
- Q-4 How many individuals in your facility have a M.S. degree in human genetics/genetic counseling? (circle the number)
- 1 ONE
  - 2 MORE THAN ONE (specify the number)\_\_\_\_\_
  - 3 NONE
- Q-5 Identify all the persons in your facility who provide direct genetic counseling services  
(circle as many numbers as apply)
- 1 PHYSICIAN
  - 2 NURSE PRACTITIONER
  - 3 NURSE
  - 4 GENETIC COUNSELOR/GENETIC ASSOCIATE
  - 5 SOCIAL WORKER
  - 6 GRADUATE STUDENT/INTERN
  - 7 OTHER (specify)\_\_\_\_\_
- Q-6 What is your current job position? (circle as many number as apply)
- 1 GENETIC COUNSELOR/GENETIC ASSOCIATE
  - 2 CLINICAL/MEDICAL GENETICIST
  - 3 CLINICAL NURSE SPECIALIST
  - 4 SOCIAL WORKER/FAMILY THERAPIST
  - 5 ADMINISTRATOR/CLINIC COORDINATOR
  - 6 CLINICAL INSTRUCTOR/FACULTY MEMBER

7 OTHER (specify) \_\_\_\_\_

Q-7 Concerning your genetic counseling-related activities,  
how often do you do the following?How often do you do these?  
(circle your answer)

- |    |                                                                                     |         |           |        |       |
|----|-------------------------------------------------------------------------------------|---------|-----------|--------|-------|
| 1  | Ask the patient about his/her expectations. . . . .                                 | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 2  | Assess the patient's cultural beliefs. . . . .                                      | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 3  | Assess the patient's education level . . . . .                                      | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 4  | Assess whether the patient is emotionally ready for the information . . . . .       | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 5  | Prepare the patient for the possibility of uncertain or shocking information .      | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 6  | Do individual counseling.                                                           | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 7  | Do group counseling . . .                                                           | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 8  | Use pre-tests and post-tests to assess the patient's understanding of the facts . . | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 9  | Assess the readability level of written materials. . .                              | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 10 | Use pamphlets and/or handouts. . . . .                                              | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 11 | Use videos and/or films .                                                           | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 12 | Ask the patient to repeat what you said in his/her own words . . . . .              | .ALWAYS | SOMETIMES | RARELY | NEVER |
| 13 | Assess the need to see a social worker/mental health worker . . . . .               | .ALWAYS | SOMETIMES | RARELY | NEVER |

- Q-8 Approximately how many hours per week do you spend on genetic counseling? (direct patient contact)  
(circle the number)
- 1 LESS THAN 5
  - 2 5-10
  - 3 11-15
  - 4 16-20
  - 5 MORE THAN 20
- Q-9 Approximately how many hours per week do you spend on clerical/administrative work?  
(circle the number)
- 1 LESS THAN 5
  - 2 5-10
  - 3 11-15
  - 4 16-20
  - 5 MORE THAN 20
- Q-10 Approximately how many patients per week do you see for genetic counseling?  
(circle the number)
- 1 ZERO
  - 2 1-9
  - 3 10-20
  - 4 21-30
  - 5 MORE THAN 30
- Q-11 Approximately how long does your genetic average counseling session last?  
(circle the number)
- 1 LESS THAN 30 MINUTES
  - 2 30-60 MINUTES
  - 3 MORE THAN 60 MINUTES
- Q-12 Approximatedly how many hours per week do you spend on genetic-related education activities in the community?  
(circle the number)
- 1 ZERO
  - 2 LESS THAN FIVE
  - 3 5-10
  - 4 MORE THAN 10

Q-13 In your opinion, how important is it that your counseling achieve each of the following?

- VI MEANS VERY IMPORTANT  
 SI MEANS SOMEWHAT IMPORTANT  
 I MEANS IMPORTANT  
 NI MEANS NOT IMPORTANT

		How Important (circle one)			
1	Prevent disease or abnormality . . . . .	.VI	I	SI	NI
2	Reduce the number of carriers of genetic disorders in the population .VI	.VI	I	SI	NI
3	Improve the general health of the population . . . . .	.VI	I	SI	NI
4	Help families adjust to and cope with their genetic disorders . . . . .	.VI	I	SI	NI
5	Remove or lessen the patient's guilt or anxiety . . . . .	.VI	I	SI	NI
6	Helping individual couples achieve their parenting goals. . . . .	.VI	I	SI	NI

Q-14 Which of the following factors listed below do you think increase your effectiveness as a counselor: (circle as many number as apply)

- 1 GENDER
- 2 RACIAL OR ETHNIC BACKGROUND
- 3 HAVING HAD CHILDREN
- 4 NOT HAVING HAD CHILDREN
- 5 PERSONAL EXPERIENCE WITH GENETIC DISORDERS
- 6 RECOGNIZING PROFESSIONAL LIMITATIONS
- 7 FORMAL TRAINING IN COUNSELING TECHNIQUES
- 8 FORMAL TRAINING IN EDUCATION METHODS AND PRINCIPLES
- 9 FORMAL TRAINING IN HUMAN GENETICS
- 10 OTHER (specify) \_\_\_\_\_
- 11 NONE OF THE ABOVE

Q-15 Which of the following factors listed below do you think limit or may potentially limit your effectiveness as a counselor: (circle as many number as apply)

- 1 GENDER
- 2 RACIAL OR ETHNIC BACKGROUND
- 3 HAVING HAD CHILDREN
- 4 NOT HAVING HAD CHILDREN
- 5 NO PERSONAL EXPERIENCE WITH GENETIC DISORDERS
- 6 NOT RECOGNIZING PROFESSIONAL LIMITATIONS
- 7 NO FORMAL TRAINING IN COUNSELING TECHNIQUES
- 8 NO FORMAL TRAINING IN EDUCATION MEHTODS AND PRINCIPLES
- 9 NO FORMAL TRAINING IN HUMAN GENETICS
- 10 OTHER (specify) \_\_\_\_\_
- 11 NONE OF THE ABOVE

GENETIC COUNSELING IS OFTEN DONE BY A TEAM OF HEALTH PROFESSIONALS. WE ARE INTERESTED IN KNOWING WHO IN YOUR FACILITY ROUTINELY DOES THE GENETIC COUNSELING-RELATED ACTIVITIES LISTED BELOW.

Q-16 Which of the following person(s) in your facility routinely do(es) the following genetic counseling-related activities? (circle as many as apply)

- MD MEANS PHYSICIAN  
 RN MEANS NURSE  
 GC MEANS GENETIC COUNSELOR/GENETIC ASSOCIATE  
 SW MEANS SOCIAL WORKER/MENTAL HEALTH PROFESSIONAL  
 NONE MEANS NONE OF THE TEAM MEMBERS

Who routinely do(es) the following?  
 (circle as many as apply)

- |   |                                                                          |     |    |    |      |      |
|---|--------------------------------------------------------------------------|-----|----|----|------|------|
| 1 | Educates the patient on what to expect in the counseling session . . . . | .MD | RN | GC | SW   | NONE |
| 2 | Constructs a pedigree . . . . .                                          | .MD | RN | GC | SW   | NONE |
| 3 | Assesses the patient's knowledge about the disorder. . . . .             | .MD | RN | GC | SW   | NONE |
| 4 | Assesses the patient's understanding about the disorder. . . . .         | .MD | RN | GC | SW   | NONE |
| 5 | Provides accurate and complete information about the disorder. .MD       | RN  | GC | SW | NONE |      |
| 6 | Describes diagnostic procedures .MD                                      | RN  | GC | SW | NONE |      |
| 7 | Discusses the benefits and limitations of each procedure . .MD           | RN  | GC | SW | NONE |      |

8	Obtains informed consent for diagnostic procedures . . . . .	.MD	RN	GC	SW	NONE
9	Calls the patient at home when a diagnosis is made . . . . .	.MD	RN	GC	SW	NONE
10	Discusses the diagnosis and prognosis with the patient. . . . .	.MD	RN	GC	SW	NONE
11	Clarifies what the physician says about the disorder. . . . .	.MD	RN	GC	SW	NONE
12	Reinforces what the physician says about the disorder . . . . .	.MD	RN	GC	SW	NONE
13	Identifies the patient's coping strategies. . . . .	.MD	RN	GC	SW	NONE
14	Helps the patient to identify his/her support systems . . . . .	.MD	RN	GC	SW	NONE
15	Discusses the impact of the disorder on the family . . . . .	.MD	RN	GC	SW	NONE
16	Discusses the available reproductive options . . . . .	.MD	RN	GC	SW	NONE
17	Discusses the available family planning methods. . . . .	.MD	RN	GC	SW	NONE
18	Assesses the need for follow-up visits. . . . .	.MD	RN	GC	SW	NONE
19	Helps the patient to recognize and to understand the emotional, cultural, and religious factors that influence decision-making . . . . .	.MD	RN	GC	SW	NONE
20	Helps the family hypothesize a variety of outcomes based on possible family planning decisions. . . . .	.MD	RN	GC	SW	NONE
21	Helps the family evaluate the impact of each potential outcome on the family . . . . .	.MD	RN	GC	SW	NONE
22	Asks the patient his/her preferred course of action. . . . .	.MD	RN	GC	SW	NONE
23	Helps the client move toward the chosen course of action . . . . .	.MD	RN	GC	SW	NONE

- |    |                                                                                            |     |    |    |    |      |
|----|--------------------------------------------------------------------------------------------|-----|----|----|----|------|
| 24 | Teaches patient how to manage the disorder . . . . .                                       | .MD | RN | GC | SW | NONE |
| 25 | Alleviates the patient's feelings of guilt, anxiety, or other emotions expressed . . . . . | .MD | RN | GC | SW | NONE |
| 26 | Is emotionally available during crisis periods . . . . .                                   | .MD | RN | GC | SW | NONE |
| 27 | Is physically available during crisis periods . . . . .                                    | .MD | RN | GC | SW | NONE |
| 28 | Assesses the need to see a social worker/mental health professional. . . .                 | .MD | RN | GC | SW | NONE |
| 29 | Refers the patient to a social worker/mental health professional. . . .                    | .MD | RN | GC | SW | NONE |
| 30 | Acts as liaison between the patient and outside agencies . . . . .                         | .MD | RN | GC | SW | NONE |
| 31 | Develops patient education materials . . . . .                                             | .MD | RN | GC | SW | NONE |

MEMBERS OF THE GENETIC COUNSELING TEAM HAVE DIFFERENT TRAINING AND SPECIALTY AREAS. HOWEVER, SOME TEAM MEMBERS MAY BE PERFORMING FUNCTIONS THAT ANOTHER HEALTH PROFESSIONAL MAY BE BETTER TRAINED OR QUALIFIED TO DO. WE WOULD LIKE TO HAVE YOUR PERSONAL OPINIONS ON WHO SHOULD BE DOING THE GENETIC COUNSELING-RELATED ACTIVITIES LISTED BELOW.

Q-17 Which of the following person(s) in your facility should routinely be doing the following genetic counseling-related activities? (circle as many as apply)

- MD MEANS PHYSICIAN  
 RN MEANS NURSE  
 GC MEANS GENETIC COUNSELOR/GENETIC ASSOCIATE  
 SW MEANS SOCIAL WORKER/MENTAL HEALTH PROFESSIONAL  
 NONE MEANS NONE OF THE TEAM MEMBERS

---

Who should do the following?  
 (circle as many as apply)

- |   |                                                                                   |     |    |    |    |      |
|---|-----------------------------------------------------------------------------------|-----|----|----|----|------|
| 1 | Educate the patient on what to expect in the genetic counseling session . . . . . | .MD | RN | GC | SW | NONE |
| 2 | Construct a pedigree . . . . .                                                    | .MD | RN | GC | SW | NONE |

3	Assess the patient's knowledge about the disorder. . . . .	.MD	RN	GC	SW	NONE
4	Assess the patient's understanding about the disorder . . .	.MD	RN	GC	SW	NONE
5	Provide accurate and complete information about the disorder	.MD	RN	GC	SW	NONE
6	Describe diagnostic procedures.	.MD	RN	GC	SW	NONE
7	Discuss the benefits and limitations of each procedure . . . . .	.MD	RN	GC	SW	NONE
8	Obtain informed consent for diagnostic procedures . . . . .	.MD	RN	GC	SW	NONE
9	Call the patient at home when a diagnosis is made . . . . .	.MD	RN	GC	SW	NONE
10	Discuss the diagnosis and prognosis with the patient. . . . .	.MD	RN	GC	SW	NONE
11	Clarify what the physician says about the disorder. . . . .	.MD	RN	GC	SW	NONE
12	Reinforce what the physician says about the disorder. . . . .	.MD	RN	GC	SW	NONE
13	Identify the patient's coping strategies. . . . .	.MD	RN	GC	SW	NONE
15	Help the patient to identify his/her support systems . . . . .	.MD	RN	GC	SW	NONE
16	Discuss the impact of the disorder on the family. . . . .	.MD	RN	GC	SW	NONE
17	Discuss the available reproductive options . . . . .	.MD	RN	GC	SW	NONE
18	Assess the need for follow-up visits. . . . .	.MD	RN	GC	SW	NONE
19	Help the patient to recognize and to understand the emotional, cultural and religious factors that influence decision-making . . . . .	.MD	RN	GC	SW	NONE
20	Help the family hypothesize a variety of outcomes based on possible family planning decisions. . . . .	.MD	RN	GC	SW	NONE

21	Help the family evaluate the impact of each potential outcome on the family . . . . .	.MD	RN	GC	SW	NONE
22	Ask the patient his/her preferred course of action. . . . .	.MD	RN	GC	SW	NONE
23	Help the client move toward the chosen course of action . . . . .	.MD	RN	GC	SW	NONE
24	Teach patient how to manage the disorder. . . . .	.MD	RN	GC	SW	NONE
25	Alleviate the patient's feelings of guilt, anxiety, or other emotions expressed. . . . .	.MD	RN	GC	SW	NONE
26	Be emotionally available during crisis periods . . . . .	.MD	RN	GC	SW	NONE
27	Be physically available during crisis periods. . . . .	.MD	RN	GC	SW	NONE
28	Assess the need to see a social worker/mental health professional	.MD	RN	GC	SW	NONE
29	Refer to a social worker/mental health professional . . . . .	.MD	RN	GC	SW	NONE
30	Act as liaison between the patient and outside agencies. . . . .	.MD	RN	GC	SW	NONE
31	Develop patient education material. . . . .	.MD	RN	GC	SW	NONE

FOLLOWING ARE SOME QUESTIONS ON YOUR TRAINING IN GENETIC COUNSELING

- Q-18 Which of the following degrees do you hold? (circle as many numbers as apply)
- 1 M.D. (specify area) \_\_\_\_\_
  - 2 Ph.D. (specify field) \_\_\_\_\_
  3. M.S. (specify degree) \_\_\_\_\_
  - 4 B.S. (specify degree) \_\_\_\_\_
  - 5 OTHER (specify field and degree) \_\_\_\_\_
- Q-19 How long have you been providing/participating in genetic counseling?  
 \_\_\_\_\_ YEAR(S)

Q-20 How long have you been providing/participating in genetic counseling in this facility?  
 \_\_\_\_\_ YEAR(S)

Q-21 What training have you had in human genetics?  
 (circle as many numbers as apply)

- 1 COLLEGE COURSE WORK IN HUMAN GENETICS
- 2 SUPERVISED CLINICAL TRAINING
- 3 SEMINARS AND/OR WORKSHOPS
- 4 OTHER (specify) \_\_\_\_\_
- 5 NONE

Q-22 What training have you had in counseling techniques?(circle as many numbers as apply)

- 1 COLLEGE COURSE WORK IN COUNSELING TECHNIQUES
- 2 SUPERVISED CLINICAL TRAINING
- 3 SEMINARS AND/OR WORKSHOPS
- 4 OTHER (specify) \_\_\_\_\_
- 5 NONE

Q-23 What training have you had in education methods and principles? (circle as many numbers as apply)

- 1 COLLEGE COURSE WORK IN EDUCATIONAL METHODS/PRINCIPLES
- 2 SUPERVISED TRAINING
- 3 SEMINARS AND/OR WORKSHOPS
- 4 OTHER (specify) \_\_\_\_\_
- 5 NONE

Q-24 Do you think only genetic counselors with master's degrees in genetic counseling should do genetic counseling? (circle the number)

- 1 YES
- 2 NO

FOLLOWING ARE SOME QUESTIONS ABOUT YOU

Q-25 Which racial or ethnic group best describes you?  
 (circle the number)

- 1 WHITE (CAUCASIAN)
- 2 BLACK (AFRICAN AMERICAN)
- 3 HISPANIC
- 4 ASIAN
- 5 OTHER (specify) \_\_\_\_\_

Q-26 What is your gender? (circle the number)

- 1 FEMALE
- 2 MALE

Q-27 Please circle as many as apply:

- 1 I HAVE A GENETIC DISORDER
- 2 I HAVE/HAD A FAMILY MEMBER WITH A GENETIC DISORDER
- 3 I HAVE/HAD A CLOSE FRIEND WITH A GENETIC DISORDER
- 4 NONE OF THE ABOVE

Q-28 Are you actively involved in any genetic support groups?  
(circle the number)

- 1 YES
- 2 NO

RESEARCH SPONSORED BY THE HUMAN GENOME PROJECT WILL RESULT IN  
RAPID ADVANCES IN OUR SCIENTIFIC KNOWLEDGE AND UNDERSTANDING  
OF GENETIC DISORDERS.

Q-29 How do you think the Human Genome Project will impact the  
field of genetic counseling?

APPENDIX 3  
EXTRA TABLES

Table A-1. Health professionals who routinely does the following genetic counseling-related activities in your facility.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Educates the patient on what to expect in the counseling session	5 3	32 21	52 34	2 1	9 6	7 5	19 12	15 10
Constructs a pedigree	10 6	18 12	50 32	2 1	1 1	13 34	17 11	0 0
Assesses knowledge about disorder	20 13	8 5	29 18	0 0	1 1	14 9	50 32	2 1
Assesses understanding of disorder	26 16	5 3	27 17	1 1	1 1	53 34	2 1	8 5
Provides information about disorder	38 24	2 1	13 6	0 0	1 1	14 9	67 43	1 1
Describes diagnostic procedures	31 20	3 2	24 16	0 0	1 1	20 13	51 32	2 1
Describes benefits and limitations of procedures	44 28	3 2	26 16	0 0	2 1	11 7	51 32	2 1
Obtains informed consent	27 17	22 14	36 23	0 0	7 4	10 6	27 17	2 1

Table A-1--continued.

Activity	RN,GC		RN,SW		GC,SW		MD,RN GC		MD,RN SW		RN,SW		MD,RN GC,SW		MD,GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Educates the patient on what to expect in the counseling session	15	10	0	0	3	1	8	5	1	1	0	0	0	0	0	0
Constructs a pedigree	17	11	0	0	2	1	10	7	0	0	0	0	1	1	0	0
Assesses knowledge about disorder	6	4	1	1	2	1	23	15	1	1	0	0	0	0	0	0
Assesses understanding of disorder	8	5	0	0	1	1	19	12	1	1	0	0	1	1	0	0
Provides information about disorder	1	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0
Describes diagnostic procedures	6	4	1	1	0	0	19	12	0	0	0	0	0	0	0	0
Describes benefits and limitations of procedures	4	3	0	0	0	0	15	9	0	0	0	0	0	0	0	0
Obtains informed consent	13	8	0	0	2	1	12	8	0	0	0	0	0	0	0	0

Table A-1--continued.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Calls patient at home when diagnosis is made	25 16	10 6	38 24	0 0	8 5	12 8	41 26	2 1
Discusses diagnosis and prognosis	45 28	3 2	13 8	0 0	3 2	12 8	65 41	2 1
Clarifies what the physician says	9 6	24 15	59 37	2 1	6 4	5 3	16 10	0 0
Reinforces what the physician says	9 6	25 16	60 38	1 1	5 3	3 2	17 11	0 0
Identifies patient's coping strategies	8 5	17 11	46 29	4 3	3 2	14 9	30 19	1 1
Helps patient identi- fy support system	7 4	15 9	45 28	6 4	3 2	11 7	25 16	0 0
Discusses impact of disorder on family	17 11	7 4	29 18	2 1	2 1	19 12	40 25	2 1
Discusses reproduc- tive options	33 21	3 2	29 18	1 1	2 1	12 8	48 31	1 1

Table A-1--continued.

Activity	RN, GC		RN, SW		GC, SW		MD, RN GC		MD, RN SW		RN, SW		MD, RN GC, SW		MD, GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Calls patient when diagnosis is made	8	5	0	0	1	1	12	8	0	0	0	0	0	0	1	1
Discusses diagnosis and prognosis	3	2	0	0	1	1	10	6	0	0	0	0	0	0	0	0
Clarifies what physician says	27	18	1	1	2	1	4	3	0	0	2	1	0	0	1	1
Reinforces what physician says	24	15	2	1	2	1	3	2	1	1	2	1	1	1	2	1
Identifies patient's coping strategies	9	6	1	1	6	4	12	8	1	1	2	1	3	2	1	1
Helps patient identify support system	10	6	2	1	7	4	17	11	1	1	3	2	3	2	1	1
Discusses impact of disorder on family	6	4	1	1	3	2	18	11	2	1	1	1	4	3	5	3
Discusses reproductive options	5	3	1	1	2	1	18	11	0	0	0	0	1	1	1	1

Table A-1--continued.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Assesses need for follow-up visits	25 16	10 6	38 24	0 0	8 5	12 8	41 26	2 1
Helps patient recognize and understand factors that influence decision	17 11	7 5	44 28	3 2	9 6	12 8	31 20	2 1
Helps family hypothesize variety of outcomes	26 17	5 3	43 27	0 0	8 5	12 8	37 24	3 2
Helps family evaluate the impact of outcome	26 17	5 3	39 25	2 1	7 5	10 6	34 22	1 1
Asks patient the preferred action	30 19	3 2	26 17	0 0	5 3	12 8	48 31	2 1
Helps patient move toward action	25 16	8 5	29 19	0 0	7 5	15 10	41 26	2 1
Teaches patient how to manage disorder	46 29	11 7	6 4	0 0	9 6	20 13	36 23	2 1
Alleviates feelings of guilt, anxiety, etc.	19 12	4 3	28 18	0 0	2 1	17 11	42 27	3 2

Table A-1--continued.

Activity	RN, GC		RN, SW		GC, SW		MD, RN GC		MD, RN SW		RN, SW		MD, RN GC, SW		MD, GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Assesses need for follow-up visits	4	3	1	1	1	1	16	10	1	1	0	0	3	2	1	1
Helps patient recognize and understand factors that influence decision	7	5	0	0	2	1	14	9	1	1	0	0	4	3	3	2
Helps family hypothesize variety of outcomes	5	3	0	0	1	1	13	8	1	1	1	1	2	1	0	0
Helps family evaluate impact of outcome	6	4	2	1	2	1	14	9	1	1	2	1	3	2	2	1
Asks patient the preferred action	3	2	1	1	1	1	21	13	1	1	0	0	0	0	2	1
Helps patient move toward action	4	3	2	1	2	1	15	10	1	1	2	1	1	1	2	1
Teaches patient how to manage the disorder	3	2	1	1	1	1	18	11	1	1	2	1	1	1	1	1
Alleviates feelings of guilt, anxiety, etc.	5	3	1	1	3	1	22	14	2	1	1	1	2	1	7	4

Table A-1--continued.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Is emotionally available during crisis	11 7	13 8	32 21	0 0	4 3	15 10	33 21	4 3
Is physically available during crisis	18 12	11 7	23 15	2 1	13 8	12 8	36 23	3 2
Assesses need to see social worker	28 18	10 3	19 12	1 1	4 3	20 13	43 27	2 1
Refers patient to social worker	42 27	14 9	18 12	0 0	4 3	11 7	39 25	2 1
Acts as liaison between patient and agencies	11 7	23 15	36 23	6 4	6 4	6 4	25 16	4 3
Develops patient education materials	8 5	12 8	51 32	0 0	19 12	11 7	25 16	1 1

Table A-1--continued.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Is emotionally available during crisis	11 7	13 8	32 21	0 0	4 3	15 10	33 21	4 3
Is physically available during crisis	18 12	11 7	23 15	2 1	13 8	12 8	36 23	3 2
Assesses need to see social worker	28 18	10 3	19 12	1 1	4 3	20 13	43 27	2 1
Refers patient to social worker	42 27	14 9	18 12	0 0	4 3	11 7	39 25	2 1
Acts as liason between patient and agencies	11 7	23 15	36 23	6 4	6 4	6 4	25 16	4 3
Develops patient education materials	8 5	12 8	51 32	0 0	19 12	11 7	25 16	1 1

Table A-1--continued.

Activity	RN, GC		RN, SW		GC, SW		MD, RN GC		MD, RN SW		RN, SW		MD, RN GC, SW		MD, GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Assesses need for follow-up visits	4	3	1	1	1	1	16	10	1	1	0	0	3	2	1	1
Helps patient recognize and understand factors that influence decision	7	5	0	0	2	1	14	9	1	1	0	0	4	3	3	2
Helps family hypothesize variety of outcomes	5	3	0	0	1	1	13	8	1	1	1	1	2	1	0	0
Helps family evaluate impact of outcome	6	4	2	1	2	1	14	9	1	1	2	1	3	2	2	1
Asks patient the preferred action	3	2	1	1	1	1	21	13	1	1	0	0	0	0	2	1
Helps patient move toward action	4	3	2	1	2	1	15	10	1	1	2	1	1	1	2	1
Teaches patient how to manage the disorder	3	2	1	1	1	1	18	11	1	1	2	1	1	1	1	1
Alleviates feelings of guilt, anxiety, etc.	5	3	1	1	3	1	22	14	2	1	1	1	2	1	7	4

Table A-1--continued.

Activity	MD no.	%	RN no.	%	GC no.	%	SW no.	%	NONE no.	%	MD&RN no.	%	MD&GC no.	%	MD&SW no.	%
Is emotionally available during crisis	11	7	13	8	32	21	0	0	4	3	15	10	33	21	4	3
Is physically available during crisis	18	12	11	7	23	15	2	1	13	8	12	8	36	23	3	2
Assesses need to see social worker	28	18	10	3	19	12	1	1	4	3	20	13	43	27	2	1
Refers patient to social worker	42	27	14	9	18	12	0	0	4	3	11	7	39	25	2	1
Acts as liaison between patient and agencies	11	7	23	15	36	23	6	4	6	4	6	4	25	16	4	3
Develops patient education materials	8	5	12	8	51	32	0	0	19	12	11	7	25	16	1	1

Table A-1--continued.

Activity	RN,GC		RN,SW		GC,SW		MD,RN GC		MD,RN SW		RN,SW		MD,RN GC,SW		MD,GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Is emotionally available during crisis	8	5	1	1	7	5	17	11	1	1	3	2	2	1	5	3
Is physically available during crisis	5	3	3	2	6	4	14	9	1	1	1	1	3	2	5	3
Assesses need to see social worker	4	3	0	0	1	1	21	13	1	1	0	0	2	1	2	1
Refers patient to socail worker	5	3	0	0	2	1	17	11	1	1	0	0	1	1	1	1
Acts as liason between patient and agencies	13	8	3	2	9	6	9	6	1	1	2	1	2	1	2	1
Develops patient education materials	9	6	0	0	1	1	15	10	1	1	0	0	2	1	3	2

Note: percentages may not add up to 100 due to rounding.

MD = physician; RN = nurse; GC = genetic associates/genetic counselors; SW = social worker

Table A-2. Health professionals who should be doing the following genetic counseling-related activities in your facility.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Educate the patient on what to expect in the counseling session	5 3	23 15	46 30	5 3	2 1	7 5	16 11	0 0
Construct a pedigree	2 1	13 8	59 37	1 1	1 1	7 5	30 19	0 0
Assess knowledge about disorder	14 9	8 5	36 24	1 1	1 1	12 8	38 25	1 1
Assess understanding of disorder	15 10	5 3	32 21	0 0	1 1	13 9	46 30	1 1
Provide information about disorder	34 22	1 1	10 7	0 0	1 1	11 7	69 45	0 0
Describe diagnostic procedures	27 18	7 5	18 12	0 0	1 1	11 7	45 30	0 0
Describe benefits and limitations of procedures	38 25	3 2	21 14	1 1	1 1	9 6	45 29	0 0
Obtain informed consent	29 19	16 11	27 18	1 1	1 1	9 6	30 20	0 0

Table A-2--continued.

Activity	RN,GC no. %	RN,SW no. %	GC,SW no. %	MD,RN GC no. %	MD,RN SW no. %	RN,SW no. %	MD,RN GC,SW no. %	MD,GC SW no. %
Educate the patient on what to expect in the counseling session	22 14	3 2	0 0	13 9	0 0	4 2	7 5	0 0
Construct a pedigree	18 11	0 0	1 1	16 10	0 0	0 0	5 3	0 0
Assess knowledge about disorder	11 7	1 1	2 1	20 13	0 0	2 1	5 3	0 0
Assess understanding of disorder	11 7	1 1	0 0	21 14	0 0	0 0	6 4	1 1
Provide information about disorder	2 1	0 0	0 0	21 14	1 1	0 0	3 2	0 0
Describe diagnostic procedures	11 7	0 0	0 0	30 20	0 0	0 0	2 1	0 0
Describe benefits and limitations of procedures	8 5	0 0	0 0	26 17	0 0	0 0	1 1	0 0
Obtain informed consent	13 9	0 0	0 0	21 14	0 0	3 2	3 2	0 0

Table A-2--continued.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Call patient at home when diagnosis is made	27 18	9 6	31 20	2 1	2 1	7 5	41 27	1 1
Discuss diagnosis and prognosis	41 27	3 1	13 9	0 0	2 1	7 5	59 39	0 0
Clarify what the physician says	8 5	14 9	55 36	1 1	3 2	8 5	16 10	0 0
Reinforce what the physician says	6 4	15 10	46 30	2 1	2 1	7 5	13 9	0 0
Identify patient's coping strategies	5 3	9 6	26 17	11 7	1 1	8 5	17 11	0 0
Help patient identify support system	5 3	7 5	28 18	14 9	1 1	8 5	16 10	0 0
Discuss impact of disorder on family	10 7	5 3	23 15	10 7	1 1	8 5	26 17	1 1
Discuss reproductive options	20 13	8 5	22 15	1 1	1 1	9 6	40 26	1 1

Table A-2--continued.

Activity	RN, GC		RN, SW		GC, SW		MD, RN GC		MD, RN SW		RN, SW		MD, RN GC, SW		MD, GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Call patient when diagnosis is made	5	3	0	0	1	1	20	13	1	1	1	1	2	1	2	1
Discuss diagnosis and prognosis	4	3	0	0	0	0	20	13	1	1	2	1	2	1	0	0
Clarify what physician says	26	17	0	0	3	2	10	7	0	0	7	5	0	0	2	1
Reinforce what physician says	35	23	1	1	4	3	9	6	8	5	1	1	3	2	2	1
Identify patient's coping strategies	11	7	1	1	17	11	17	11	0	0	8	5	12	8	10	7
Help patient identify support system	9	6	3	2	17	11	14	9	2	1	5	3	17	11	6	4
Discuss impact of disorder on family	8	5	0	0	8	5	17	11	2	1	3	2	20	13	10	7
Discuss reproductive options	11	7	0	0	2	1	22	15	0	0	2	1	8	5	5	3

Table A-2--continued.

Activity	MD no. %	RN no. %	GC no. %	SW no. %	NONE no. %	MD&RN no. %	MD&GC no. %	MD&SW no. %
Assess need for follow-up visits	30 20	7 5	11 7	3 2	1 1	8 5	47 31	1 1
Help patient recognize and understand factors that influence decision	8 5	9 6	27 18	9 6	3 2	6 4	21 14	1 1
Help family hypothesize variety of outcomes	6 6	7 5	33 21	7 5	1 1	4 3	24 16	3 2
Help family evaluate the impact of outcome	13 9	4 3	26 17	6 4	1 1	5 3	26 17	1 1
Ask patient the preferred action	26 17	6 4	23 15	2 1	2 1	8 5	35 23	3 2
Help patient move toward action	16 11	6 4	23 15	3 2	3 2	8 5	37 25	1 1
Teach patient how to manage disorder	30 20	11 7	7 6	0 0	1 1	20 13	31 21	1 1
Alleviate feelings of guilt, anxiety, etc.	10 7	4 3	18 12	1 1	2 1	10 17	27 18	2 1

Table A-2--continued.

Activity	RN,GC		RN,SW		GC,SW		MD,RN GC		MD,RN SW		RN,SW		MD,RN GC,SW		MD,GC SW	
	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%	no.	%
Be emotionally available during crisis	3	2	4	3	14	9	18	12	2	1	4	3	26	17	11	7
Be physically available during crisis	1	1	3	2	10	7	20	13	2	1	8	5	15	10	10	7
Assess need to see social worker	5	3	2	1	25	17	1	1	1	1	25	17	11	7	1	1
Refer patient to social worker	6	4	1	1	1	1	26	16	1	1	2	1	23	14	5	3
Act as liaison between patient and agencies	10	7	3	2	17	11	13	9	1	1	10	7	12	8	5	3
Develop patient education materials	7	5	0	0	2	1	22	15	1	1	8	5	24	16	5	3

Note: percentages may not add up to 100 due to rounding.

MD = physician; RN = nurse; GC = genetic associates/genetic counselors; SW = social worker

APPENDIX 3  
GENETIC COUNSELING PROGRAMS

APPENDIX 3  
GENETIC COUNSELING PROGRAMS

Master's Level Genetic Counseling Programs

Jon Weil, PhD  
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University of California at Berkley  
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Ann P. Walker, MA  
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Anne Matthews, RN, PhD  
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Univ. Colorado Health Sciences Center  
The Children's Hospital  
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Denver, CO 80218  
(303) 837-2760

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Director, Graduate Studies  
Howard University College of Medicine  
Division of Medical Genetics  
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Beth Fine, MS  
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Prentice Women's Hospital  
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Kim Quaid, PhD  
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Jacqueline Hecht, PhD  
Director, Genetic Counseling Program  
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Department of Pediatrics  
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(713) 797-5330

Joann Bodurtha, MD, Director  
Medical College of Virginia/Virginia  
Commonwealth University  
Department Human Genetics Box 33  
Richmond, VA 23298-0033  
(804) 786-9632

Joan Burns, MS. MSSW  
Genetic Counseling Program  
University of Wisconsin  
Waisman Center Room 331  
1500 Highland Ave.  
Madison, WI 53706  
(608) 263-5611

Graduate Nursing Programs

Cecily Betz, RN, PhD  
Associate Director  
UCLA-UAP  
UCLA Neuropsychiatric Institute  
Los Angeles, CA 90024  
(310) 825-8902

Elizabeth Thomson, RN, MS  
University of Iowa  
College of Nursing  
Iowa City, IA 52242  
(319) 356-2674

Mary Challela, DNSc, RN  
Director of Nursing  
Shriver Center  
200 Trapelo Road  
Waltham, MA 02254  
(614) 642-0268

Barbara Engstrom-Berling, MSN, RN  
Graduate Program in Parent-Child Nursing  
University of Cincinnati  
College of Nursing and Health  
Cincinnati, OH 45229-2899  
(513) 559-4616

Program For Persons With A Master's Or Doctoral Degree In A  
Related Field

Randi Zinberg, MS  
Genetic Counseling Certification Program  
Mt. Sinai Hospital  
100th & Madison Avenue  
New York, NY 10029  
(212) 241-6947

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## BIOGRAPHICAL SKETCH

Delores Corinne Suzette James was born in St. John's Antigua, West Indies. She graduated from the Antigua Girls' High School; the Ohio State University in Columbus, Ohio, in 1984 with a Bachelor of Science in Allied Medical Professions, with a major in medical dietetics.

After completing her undergraduate work, Ms. James worked for five years as a public health nutritionist in the Department of Obstetrics and Gynecology, University of Florida. She is a registered and licensed dietitian.

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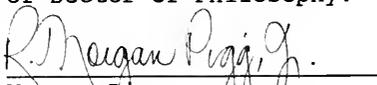
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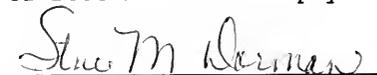
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Lee Crandall  
Professor of Sociology

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Morgan Pigg  
Professor of  
Health Science Education

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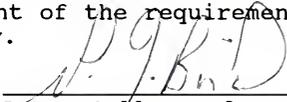
  
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This dissertation was submitted to the Graduate Faculty of the College of Education and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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