

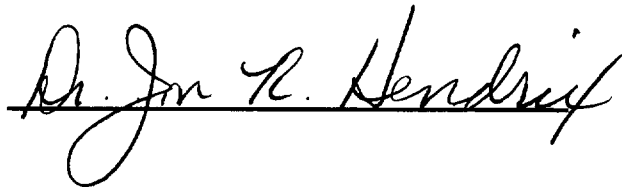
Bioethics Education of Genetic Counselors

An Honors Thesis (Honors 499)

by

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A handwritten signature in cursive script that reads "Dr. Jon R. Hendrix". The signature is written in black ink and is positioned above a horizontal line.

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understanding their implications, making decisions about what course to follow and working through psychological and social aspects as they affect individuals or couples" (Witmar, 1986). It is also the responsibility of the genetic counselor to perform ethically using "...autonomy, beneficence and nonmaleficence, fidelity in the relationship, and fairness or equality" as major ethical principles to guide them in their professional work (Witmar, 1986). The role of the genetic counselor becomes crucial in being the dispenser of genetic knowledge to humans in need of such knowledge. It is with this responsibility that genetic counselors confront and deal with ethical, legal and professional problems. The National Society of Genetic Counselors (NSGC) includes over 1040 members and has its own code of ethics which "...affirms the ethical responsibilities of its members and provides them with the guidance in their relationships with self, clients, colleagues, and society"(NSGC, 1993). Margaret Mead (1974) describes the responsibility of society to act with:

Willingness to protect life as an individual understands it, and to protect the individual's conscientious choice, and the willingness to find a place for the weak, the infant and the aged, the crippled, the defective, mutilated by accident or war, are a measure of a good society. But this is only so if this willingness is joined by the most vigorous attempt to abolish the conditions that make these decisions so paradoxical, contradictory, and difficult.

The field of genetic counseling has evolved during the past three decades. In 1969, the first master's genetic counseling training program was established at Sarah Lawrence College in Bronxville, New York. Since then, there has been the implementation of 23 other programs, including 16 in the U.S., 1 Canadian, 2 international (South Africa and England), and 4 nursing programs. By the year 2002, the expected number of master's degree genetic counselors approaches 2200 (Smith, A.C.M., 1993). Three meetings were held in the 1970's aimed at discussing the role, function, and the training needed in genetic counseling as new information is discovered. As a result, the recommended curricula for master's degree programs in genetic counseling were didactic course work which consisted of basic science, counseling theory and techniques, clinical practicums, and some laboratory practica (Smith, A.C.M., 1993). NSGC with funding from the Ethical, Legal, and Social Implications Program (ELSI) of NCHGR sponsored a conference in June of 1992, for genetic

counselor and clinical nurse specialist graduate program directors to discuss four issues resulting from information available through research on the Human Genome Project. These issues dealt with views on human variation and diversity, genetic discrimination, potential new threats to non-directiveness, and genetic screening and policy development (Biesecker, 1993). Three general professional goals of genetic counselors beginning their careers have been established as a formal verification of competence either by an American Board of Medical Genetics (ABMG) examination or licensure, maintenance of expertise through continuing education activities, and professional advancement (Scott, 1988).

In an article by B.S. LeRoy (1992), the director of the graduate program in genetic counseling at the University of Minnesota, the following data were noted: of 18 schools surveyed (the only ones with graduate genetic counseling programs), only four had a formal course in bioethics required for a degree in genetic counseling, other programs incorporated the bioethics component within other courses. This researcher believes that creating ethical awareness is of utmost importance in the education of genetic counselors; to that end, this research is directed.

The Purpose

As a result of the enormous amounts of information generated by the Human Genome Project, the need for genetic counselors to interpret and deliver this knowledge to society becomes evident. Moreover, genetic counselors need to become trained ethically to deal with this new information so that no harm may arise to clients, counselors, and society. Therefore, **this study is aimed at ascertaining the perceived needs of practicing genetic counselors with respect to their bioethics education.** A survey instrument was developed and sent to a randomly selected sample of genetic counselors. The survey sought information in the frequency these genetic counselors encountered specific bioethical issues, and how confident these genetic counselors feel their bioethics training has prepared them to effectively deal with these situations. The responses were used as a basis of evaluating syllabi of bioethics courses from master's degree genetic counseling training programs in providing adequate instruction.

The Hypothesis

Based on initial research on the subject, this researcher hypothesizes that genetic counselors are receiving minimal bioethics training which may not be sufficient for the decisions with which genetic counselors help their clients deal.

Definition of terms

Genetic Counselor: Health professionals who work with individuals and families with a medical history or increased risk for having a child with a birth defect or genetic condition. They provide information and supportive counseling, coordinate testing and put families in touch with community resources such as support groups and funding agencies. Genetic counselors are also involved in teaching, research, screening programs and the coordination of support groups. (NSGC, 1990).

Human Genome Project: The goal of this project is to equip biomedical researchers with the tools they need to search for genes quickly and cheaply by identifying the full set of genetic instructions contained inside our cells (mapping) and to read the complete text written in the language of the hereditary DNA (sequencing). This 15 year endeavor receives a budget of \$200 million a year and is headed by the National Institutes of Health (NIH) and the Department of Energy (DOE).

National Society of Genetic Counselors (NSGC): An organization that furthers the professional interests of genetic counselors, promotes a network for communication within the profession, and deals with issues relevant to human genetics.

National Center of Human Genome Research (NCHGR): This program was established in 1989 as the component of NIH that manages the Human Genome Project (HGP). They coordinate NIH-supported genome research conducted by other groups such as federal agencies, industry, non-profit organizations, and researchers in foreign countries.

Ethical, Legal, and Social Implications (ELSI): This program is an element of the HGP in charge of anticipating the ethical, legal, and social consequences resulting from the new knowledge acquired through HGP.

ELSI is also responsible for developing policies for dealing with conflicts and guiding the use of genome information.

Bioethics: The study and/or application of ethical or moral principles to issues and problems arising within the context of the life sciences.

Justice -1) the fair treatment of clients by being unbiased towards sex, race, religion, socio-economic status, or sexual orientation. 2) obeying the law.

Informed consent - providing necessary facts to the client in order to enable their decision-making processes.

Confidentiality- to hold private any personal information disclosed by the client either through conversation or by documented materials (e.g. medical records, test results).

Non-maleficence - the obligation not to cause harm to the client (e.g. exploitation of the client for personal advantage, profit, or interest).

Truth-telling - providing, to the client, all pertinent information about the diagnosis or case as to the best ability with respect to updated research and information available.

Autonomy - allowing the client to make a decision free from coercion or without being directed by others in making a decision.

Beneficence - to do the greatest amount of good, in respect to the client.

Paternalism - restricting the liberty of the client without their consent, or justifying such actions as to prevent some harm or to produce some benefit, when exploring alternate choices with the client.

Fidelity - the strict observance of promises and duty as a counselor.

Assumptions of this study

- 1) The respondents are truthfully answering the survey items.
- 2) The survey items are clear and serve the same meaning to all respondents.
- 3) The researchers are evaluating the bioethics training programs without bias.
- 4) The methods of determining this sample group were not biased.

Methods

The study was initiated with a review of literature on the bioethics education of genetic counselors to establish a need for this research. A questionnaire to be mailed to a sample of participants was developed, following the suggested procedures in Questionnaires: Design and Use by Berdie (1986). A sample size of 100 genetic counselors, with an expected 80% response rate, was determined to be statistically significant. A random sample of 100 genetic counselors from a NSGC mailing list was selected using a random numbers table. The study was approved by Ball State University's IRB, and the researchers were awarded a fellowship with which to complete the study. The survey items were developed on the basis of several references (Encyclopedia of Bioethics, NSGC Code of

Ethics, and "Ethics and Genetics: An International Survey of Social Science, Ethics, and Law." by the Shriver Center in Waltham, MA. The survey items were designed to ascertain: whether the understanding of bioethical principles was held among the respondents, the importance of different principles to the respondents, how many cases per year the counselors had in which they encountered different bioethical principles, and to what degree the counselors felt their bioethics education had prepared them in dealing with these cases. Several items dealt with conflicts between client's rights, counselor's rights, and societal good. The in-service experiences of the genetic counselors were also surveyed, as well as a narrative about their bioethics preparation. Demographic data were examined to establish the background of the respondents.

A test sample of five genetic counselors was sent the survey and asked to make suggestions to clarify the meaning of survey items, to improve the survey format, and to develop a structure of recording responses. From their responses, modifications to the survey were made and our 55 item survey was the final product (see Appendix A for test and final drafts of the survey, and cover letters to the test and survey samples).

The surveys were given correlation numbers, only known to the researchers, to protect the anonymity of the respondents, and a cover letter detailing the purpose of the study was sent out with the surveys. Return envelopes were provided with which to send back the completed surveys. Follow-up postcards were sent seven weeks after the initial mailing reminding the participants to respond.

A list of master's degree genetic counselor training programs in the United States, not including nursing programs, was generated from a NSGC list of accredited training sites of programs, and articles by Scott, J.A. et al. (1988) and Mertens, T.R. et al. (1986). A letter requesting syllabi of bioethics courses offered, or related materials was sent to the 16 schools. Follow-up postcards were sent two weeks after the first correspondence (see Appendix B for syllabus request letter and follow-up postcards).

The data from the returned surveys were recorded on a database created in Microsoft Works for the Macintosh computer. The averages of the responses on Likert scale items were taken, frequency counts of the numbered items were taken and percentages rounded to the nearest whole percent were computed. Several tables of the data were constructed and narratives of the responses were written. Syllabi of bioethics training courses were evaluated on their content (readings, lectures, discussions,

papers) in respect to the bioethical principles addressed in the survey. Needs in certain areas of bioethics education, conveyed by the responding genetic counselors, were noted in the conclusions.

Literature Reviews

Significance of this study

The importance of this study is based on an article by B.S. LeRoy (1992) titled "Bioethics Education in Genetic Counseling Graduate Programs". The article reported findings from a survey of academic programs offering master's degrees in genetic counseling, specifically the incorporation of bioethics education in the curricula. At the time of the survey, there were 16 programs for genetic counselors and two for nursing students. One of the nursing programs had just been initiated and had not yet accepted students, but was interested in incorporating bioethics materials into the program. The other 17 programs stated that some degree of bioethics was included in their programs. Of the 17 programs, nine presented this bioethics information in a formal course. However, only four of the nine programs required their students to take this course for degree requirements. All 17 programs considered bioethics an important aspect of education programs for Genetic Counselors and were interested in obtaining course materials for teaching bioethics specifically to medical geneticists and genetic counselors.

The scope of bioethics evolved amongst conflicts between new capabilities due to technological advancements and individuals values. The ethical and legal framework established by codes of bioethics were designed to resolve strife between physicians and patients, and between social consensus and individual values. In 1990, the Ethical, Legal, and Social Implications (ELSI) program was given the responsibility of research and education of ethical, legal, and social concerns through funding by the National Institutes of Health (NIH) and the Department of Energy (DOE). 5% and 3%, respectively, were allotted from their genome budgets. With these bioethics endeavors, substantially more emphasis is placed on preventative ethics which is interested in avoiding conflicts by creating and preserving trust and understanding in provider-recipient relationships, and in maximizing ethical behavior (e.g. respect for

autonomy, informed consent, confidentiality, beneficence). It is suggested, in the article by Parker (1994) that bioethics education be incorporated into all aspects of the training program for human geneticists, namely through a case-oriented approach. The curriculum should raise ethical awareness of available ethical resources, including human resources (ethics consultants and committees, and institutional review boards) and published resources (governmental and institutional guidelines and bioethics literature). The goal of ethical education is to improve relations among health care providers and their clients, as well as promoting the acceptance by society of new medical technology.

The Role of Genetic Counselors

J. Melvin Witmar et al. (1986) establish in "Genetic Counseling: Ethical and Professional Role Implications" the purpose of genetic counselors to "...assist people in identifying potential or manifest genetic problems, understanding their implications, making decisions about what course to follow, and working through psychological and social aspects as they affect individuals or couples." There is an observed interplay of medical technology, social norms, and individual choices. Consequently, genetic counseling situations are encompassed with ethical issues pertaining to autonomy, beneficence, nonmaleficence, fidelity in the relationship, and fairness or equity. The genetic counselor plays two roles: educational and psychological. In the educational role, the counselors' objective is to provide information about the nature of the disorder, whether there is effective therapy, probabilities of occurrence in relatives, and available options. In the psychological role, the counselor is supportive in dealing with the emotional aspects of the problem, working through moral and ethical issues involved with decision-making, and addressing cultural and community attitudes and practices.

Need for Genetic Counselors

"Physicians and patients are ill prepared for this brave new world." as stated in an article in Consumer Reports (1990) titled, "The Telltale Gene." Physicians are weary about using genetic tests because the necessary counseling and education of clients are both time consuming and low in indemnities. In 1990, at least 16 states required genetic information about adoptees and their biological families. Genetic screening tests are mandatory before arranged marriages among Hasidic

Jews in some communities to avoid the pairing of two carriers for Tay Sachs. Certain employers and insurance companies are considering the use of genetic data to screen applicants for health risks such as, cancer and heart disease. Genetic testing has become a norm in obstetrical care, thereby allowing physicians to foresee future problems and even determine the sex of the fetus. This information may usher parents into having to make difficult decisions. In many cases the parents are unaware that genetic tests are being performed on their newborns. However, physicians are pushed to perform genetic tests to avoid lawsuits charging the failure to inform. As the Human Genome Project progresses and new information is available to decode our genetic secrets, society should be cautioned about the consequences of this predictive knowledge in enabling the discrimination of certain people.

J.A. Scott et al. (1988) reassesses the propriety of recommendations for genetic counselor training programs made at Williamsburg in 1979. A survey of 32 employers of genetic counselors was conducted by Kessler (1979) to ascertain specific expectations regarding the knowledge and skills of genetic counselors. Knowledge of genetic fundamentals ranked the highest among the survey items. Administrative skills and psychosocial fundamental ranked the lowest. Discrepancies in the data revealed that everyday competencies such as, preamniocentesis, supportive counseling, and knowledge of community resources were viewed as being important, but the areas of knowledge required for these competencies were ranked as relatively unimportant. Kessler concluded that the employers knew which skill they wanted, but they were not aware of where they were developed. The problem of evaluating programs is that there are not direct extramural methods of monitoring the adequacy of program curricula. The quality of the academic training of genetic counselors is determined indirectly by the performance of graduates on the American Medical Board of Genetics (AMBG) examinations. A survey administered by Finley (1987) asked medical genetics programs to anticipate the need for genetic counselors. The respondents estimated there would be a 45 percent increase in the number of genetic counselors employed by these centers within five years. Collins (1987) reports that the employment of genetic counselors has shifted from university medical center genetics units to private practices, clinics (5.8%), health maintenance organizations (3.7%), and private diagnostic labs (1.7%).

Genetic Counseling Training Programs

A conference including genetic counseling and clinical nurse specialist graduate training program directors was hosted in 1992, by NSGC and funded by ELSI to deal with the implications of the Human Genome Project. The themes were: human variation and diversity, genetic discrimination, potential new threats to non-directiveness, genetic screening, and policy development. Recommendations in the article (Biesecker, 1993) were made to enhance the curricula by addressing these five themes. Genetic counselors will progressively play more of a role in determining how the knowledge and technology generated by the Human Genome Project will be used. Counselors will also be needed to educate the public about this new information and how to deal with the ethical, social, and legal issues that may arise.

Data obtained from a survey requesting the number of actual contact hours spent by master's degree genetic counseling students in their two year course of study was reported in an article by Ann C. M. Smith (1993). The survey was sent to directors of 17 master's degree genetic counseling training programs in the United States and Canada. The genetic counseling trainees averaged a total of 1349 actual contact hours. 58% of these hours are spent on clinical practica, 21% on didactic coursework in the basic sciences, 16% in counseling preparation, and 5% in laboratory practica. These findings were compared to a similar study administered in 1989. It was found that the number of contact hours had increased which could be attributed to the increase in didactic coursework.

Ann P. Walker et al. (1989) reported findings of the Asilomar meeting on the education of genetic counselors organized by the Education Committee of NSGC. There were 35 participants ranging from representatives from genetic counseling and genetic nurse specialist programs, employers from university and state genetics programs, counselors from various work settings, graduate administrators, and several organizations such as, the March of Dimes, the Alliance of Genetic Support Groups, ABMG, and the Office of Maternal and Child Health. Guidelines for the recommended curriculum were developed based on the intent of preparing students for the ABMG examination for certification as a genetic counselor. These guidelines were to be applied to both programs offering a master's degree in genetic counseling and a master's of nursing

as a clinical nurse specialist in genetics. The recommendations were designed so as to not diminish unique strengths of individual programs. In the didactic coursework area, it was recommended to reinforce classwork with experiential training such as, clinics, case conferences, ward rounds, and laboratories. The development of the students' competence in research and professional writing was encouraged. As well as the determination to continue self education. Suggestions for a doctorate program for genetic counselors were made to include a short-term training program in specific areas such as family therapy, cancer risk assessment, and administration. Arguments against the development of a doctoral program are that two classes of genetic counselors could be created which would cause a schism between theory and practice of genetic counseling.

Data Reportings

Demographics

The average number of years the respondents were qualified to be certified as genetic counselors was 7.23 years. The range was from 1-20 years. The respondents averaged 7.85 years of service as genetic counselors. The range of years of service was 1-20 years.

Table 1
Geographic Regions, Percentage of Respondents (Number of Respondents), Number of Schools in Regions, and Number of Syllabi Returned from Regions.

Geographic Regions	% Respondents	# Schools in Regions*	#Syllabi
1: CT, ME, MA, NH, RI, VT	5.4 (2)	1	
2: DE, D.C., MD, NJ, NY, VA, WV	46 (17)	4	1
3: AL, FL, GA, KY, LA, MS NC, SC, TN	5.4 (2)	1	1
4: AR, IL, IN, IO, KS, MI MN, MO, NE, OH, WI	16.2 (6)	6	5
5 AZ, CO, MT, NM, ND, OK SD, TX, UT, WY	13.5 (5)	2	
6: AK, CA, HI, ID, NV, OR, WA	13.5 (5)	2	

* Scott, J.A. et al. 1988., Mertens, T.R. et al. 1986., NSGC list of accredited training sites of masters level genetic counselling training programs.

Table 1 shows that Region 2 (DE, D.C., MD, NJ, NY, PA, VA, WV) comprised of 46% of the survey sample. Four out of the 16 schools having a master's program in Genetic Counseling were located in this region. Region 4 (AR, IL, IN, IO, KS, MI, MN, NMO, NE, OH, WI) included six schools but consisted of only 16.2% of the sample. Both Region 1 and 3 consist of 5.4% of the respondents, respectively, and have one school. Regions 5 and

6 both include 13.5% of the respondents, respectively, and have two schools. We received responses from seven schools about their bioethics training programs. Five schools responded from Region 4, one from Region 2, and one from Region 3.

Table 2
Location and Setting of Work

Location of Work	% Respondents	Setting of Work	% Respondents
Metropolitan Area Central City	44 (16)	University-based Clinical Gen. Prog.	50(18)
Metropolitan Area	28 (10)	Hospital-based Clinical Gen. Prog	22 (8)
Small City or Town	28 (10)	Independent Center	5.6(2)
Rural	0	Community clinic	5.6(2)
		Other	16.7(8)

Table 2 shows the largest percentage (44%) of the respondents do most (over 50%) of their work in the central part of a metropolitan area. This may reflect larger hospitals or clinics, located in these areas, with more specialized programs or resources. Fifty-six percent of the respondents do most of their work in the suburbs of metropolitan areas and small cities. None of the respondents reported doing most of their work in the rural areas. Fifty percent of the respondents predominantly work in university-based clinical genetics programs. Reasons why a large percentage of respondents are working in this setting may be because the need for genetic counselors has not yet been established in other settings, they are working in conjunction with medical schools or research facilities, or working in cooperation with in-vitro fertilization clinics. While, 33.2% of the respondents work in hospital-based clinical genetics programs, hospital owned or managed by a religious organization, independent medical genetics centers, and community health clinics. The remaining 16.7% of the respondents work in "other" settings such as: 1) large multidisciplinary health care centers, 2) HMO or HMO-Kaiser Permanente, 3) private perinatology clinics and 4) large private group practices.

The majority (31%) of the respondents serve approximately 300-499

The majority (31%) of the respondents serve approximately 300-499 clients per year. This figure can be broken down to about 10 clients per week or 2 clients per day. This seems to be a reasonable number, considering the intake session, counseling time, and follow-up session per client. On the extremes of the spectrum, 2.8% of the respondents answered that they serve >1000 clients per year. While, 5.6% serve <50 clients per year.

Of the 37 respondents, 31 were female and 6 were male.

Thirty-two percent of the respondents claim that their personal faith statement (religious convictions) were important to their counseling work. Of this 32%, the effect of their faith leaned slightly towards no influence on the Likert scale in altering their ability to counsel their clients.

The respondents strongly agree that their training and experience had prepared them in dealing with the ethical issues they encounter in their professional activities.

Of the 14 respondents who answered Item 11, 29% declared that their undergraduate bioethics program **was** helpful to them. Seventy-one percent responded that an undergraduate bioethics program **would have been** helpful. These respondents strongly agree that an undergraduate bioethics course **was/would have been** helpful, therefore, indicating more of a need for undergraduate bioethics courses.

When asked if they feel that pre-service preparation is more important than in-service preparation, the respondents answered that they were neutral or slightly disagreed. It could be concluded that they feel the experiences they have gained while counseling have been more valuable than the practices encountered during training.

Bioethics Training

* for Likert scale items refer to Tables 4 and 5

Justice (items 13-18)

The definition used for justice in this survey was the fair treatment of clients by being unbiased towards sex, race, religion, socio-economic status, and sexual orientation. The respondents indicated strong agreement that counselors should abide by the principle of justice. Out of 34 respondents, 24% reported that they did not have any cases in which problems with justice were encountered. Thirty-eight percent claimed having 1-3 cases per year and 12% responded with 5-9 cases per year. Twenty-six percent had more than 10 cases per year. The respondents were neutral in whether their bioethics training has prepared them in dealing with cases of justice in respect to patient contact. Therefore, the principle of justice may need more attention in training.

The respondents agreed that it is important to act justly when counseling, by obeying the law. In their yearly practice, 3% reported greater than 10 cases dealing with problems of legal justice, 3% claimed 6-7 cases, 17% declared 1-3 cases, and 78% affirmed zero cases dealing with problems of legal justice. The respondents were neutral in feeling prepared to deal with cases of justice in respect to the law. Therefore it can be concluded that genetic counselors may not be sufficiently informed on the laws affecting the profession.

When comparing the responses in items 14 and 17, it is interesting to see 26% of the respondents reporting that they had greater than 10 cases per year dealing with problems of justice in respect to client contact. Yet, 78% claimed that they had zero cases dealing with justice in respect to the law. This points to differences in the definition of justice in respect to the treatment of clients by genetic counselors, and how genetic counselors must act in accordance to the law.

Informed Consent (items 19-21)

The respondents strongly agreed that it is important for counselors to enable their clients to make informed decisions by providing necessary facts. Seventy-six percent of the respondents have 75%-100% of their cases addressing the issue of informed consent. Five percent claimed that in their yearly practice, they did not encounter any cases dealing with informed consent. Of the remaining 19%, they encounter the issue of informed consent in 1%-74% of their cases. Most respondents felt that

their bioethics training was adequate in preparing them to deal with cases of informed consent.

Confidentiality (items 22-24)

Most respondents are in strong agreement that the counselor holds the responsibility of keeping confidential any personal information received from the client. Fifty-nine percent of the respondents have under 50% of their yearly cases dealing with problems of confidentiality and 41% have over 50% of their cases dealing with problems of confidentiality. The respondents strongly agree that their bioethics training has prepared them in dealing with cases of confidentiality with respect to releasing documented information (e.g. medical records, test results) or any information disclosed to them by their client. Variations in the responses to items 22, 23, and 24 reveal a wide range of confidentiality concerns. Therefore, the researcher has concluded that the respondents do not personally have a problem with maintaining confidentiality but their work environments may not be as conducive to do so.

Nonmaleficence (items 25-27)

The respondents strongly agreed with the definition of nonmaleficence to be the obligation not to cause harm to the client by exploitation of the client for personal advantage, profit, or interest. Eighty percent of the respondents reported having 0-3 cases dealing with nonmaleficence. Twenty percent of the respondents have had four to greater than 10 cases dealing with nonmaleficence. There may be more of a need in addressing the issue of nonmaleficence in the training of genetic counselors because the respondents were neutral in feeling that their bioethics training had prepared them to deal with this principle.

Truth-Telling (items 28-30)

The respondents feel strongly about their obligations to always tell their client the whole truth, by providing all pertinent information about the diagnosis or case. The largest percentage (75%) of the respondents have had less than 50% of their yearly cases dealing with truth-telling, while 25% of the respondents have had 75%-100% of their cases dealing with this principle. The respondents agree that their bioethics training has prepared them in dealing with cases of truth-telling.

Autonomy (items 31-33)

The respondents strongly agree that counselors should allow their clients to make their own decisions, after being provided all necessary information, free of coercion (autonomy). Fifty percent of the respondents have had 75%-100% of their yearly cases dealing with the principle of autonomy. Thirty-eight percent of the respondents have 1%-74% of their cases dealing with the issue and 11% have none. The respondents agree that their bioethics training has prepared them in dealing with cases of autonomy.

Beneficence (items 34-36)

The respondents agree it is compulsory as a counselor to always do the greatest amount of good (beneficence) in consideration of their clients. Of the 32 respondents, 66% claimed that 75%-100% of their cases in their yearly practice dealt with beneficence. Thirty-two percent had 1%-74% of their cases dealing with the issue and 3% did not have any. The respondents agree that their bioethics training has prepared them to deal with cases of beneficence.

Paternalism (items 37-39)

Paternalism is the act of restricting the liberty of clients without their consent, or justifying such actions as to prevent some harm or to produce some benefit. The respondents were in strong agreement that genetic counselors should avoid being paternalistic when exploring alternative choices with their clients. Seventy-eight percent of the respondents had fewer than 50% of cases dealing with paternalism, while 32% had greater than 50%. The respondents agreed that their bioethics training had prepared them in dealing with paternalism when counseling their clients.

Fidelity (items 40-42)

The respondents strongly agree that counselors should always act with fidelity which is the strict observance of promises and duties. Fifty-eight percent of the respondents had 75%-100% of their yearly cases dealing with fidelity. Fifteen percent of the respondents had 35%-74% of their cases dealing with the issue and 27% had 0-34% of their cases dealing with fidelity. The respondents agreed that their bioethics training had prepared them to deal with issues of fidelity in the counseling relationship.

When asked about conflicts between their client's rights and the genetic health of societal members such as, having children with genetic defects, or disturbing the proportion of a males to females in the population by choosing the sex of child, 53% had less than 1 case in which they encountered these conflicts. While 33% had 1-10 cases and 11% had greater than 10 cases. The respondents were neutral in feeling prepared by their bioethics training to deal with conflicts between client's rights and the genetic health of society.

In cases of conflicts between the client's rights and the counselor's personal beliefs, 14% had none, 56% had 1%-9%, 22% had 10%-34%, and 9% had 50% or more of these cases. Seventy-three percent of the respondents have been able to accept their client's decisions when there have been conflicts between a counselor's beliefs and a client's rights. The respondents agree that their bioethics training has prepared them to deal with these situations.

Table 3
In-Service Programs and Average Number
Experience with Programs
In the Past Year

Program	Avg. # in past year
Attendance in post graduate lectures or seminars	4
Additional College-level bioethics courses	3
Observation of other genetic counselors	4
Participation in practicums or internships	3
Participation in bioethics forums	3
Attendance and participation in professional meetings	3
Reading of current journals	5

The number of in-service programs was measured on a scale of one to greater than five. Therefore, table 3 shows that the respondents averaged quite high on their experiences with the above in-service programs.

The respondents replied that their pre-service preparation would have been better if: they had more formal courses in bioethics addressing the bioethical principles, their bioethics courses addressed bioethical principles as components of cases studies or situations specific to genetic counseling, they were given cases addressing ethical dilemmas, they had been exposed to and taught to deal with conflicts between client's rights and counselor's beliefs, and if their courses had addressed the "two-tier health care system" which divides clients into those who can afford private health care insurance and those who cannot afford insurance.

Table 4
Strongly Agree and Agree Likert Scale Items
Item Number and Average Score
(1=Strongly Agree, 2=Agree)

Item #	Avg. Score	Item #	Avg. Score
10	2.3=A	30	2.2=A
11	1.7=A	31	1.1=SA
13	1.2=SA	33	1.9=A
16	1.6=A	34	1.6=A
19	1.1=SA	36	2.2=A
21	1.8=A	37	1.3=SA
22	1.2=SA	39	2.0=A
24	2.0=SA	40	1.2=SA
25	1.5=SA	42	2.2=A
28	1.5=SA	47	2.0=A

Table 5
Neutral Likert Scale Items
Item Number and Average Score
(Neutral=2.5 to 3.5)

Item #	Avg. Score
12	3.3
15	2.5
18	3.2
27	2.5
44	2.5

Bioethics programs

Seven schools responded with information about their bioethics training programs. Of the seven programs, four programs required a formal course which incorporated bioethics. One program had seminar discussions on bioethics. Another program conducted a two-hour lecture on bioethics and one program was in the process of creating a course in ethical and legal issues in genetics. Of the four programs requiring a formal course, only one program mentioned in their syllabus, most (five out of nine) of the bioethical principles addressed in the survey. However, the extent to which these principles were covered was difficult to ascertain from the syllabus. The other three programs requiring a formal course including bioethics only covered two or three of the principles on the survey. A syllabus of an elective course in bioethics was submitted by one of the schools. The content of the course was quite inclusive, covering six of the nine principles. Some of the other topics addressed in the syllabi were health care, law, and culture; but once again the depth of these issues was not clear.

Conclusions

The responses to the survey indicated a need for more training in the principles of justice, non-maleficence, and in conflicts between client's rights and the genetic health of society. Inadequacies in the bioethics training of genetic counselors demonstrated in the evaluations of the course syllabi, affirm the lack of satisfactory training felt by the counselors. The findings on the bioethics courses and the expressed needs

of the genetic counselors about their bioethics education indicate that the master's degree genetic counselor training programs are not sufficiently addressing the bioethical principles and educating genetic counselors to confront cases that deal with bioethical dilemmas. These needs will become more evident as information about genetics is increased due to research on the Human Genome Project and as genetic counselors are faced with new diagnostic technologies. Therefore, the researchers suggest that genetic counselor training programs increase: 1) the teaching of bioethical principles, particularly the ones in the code of ethics from NSGC, and 2) the use of decision-making models. These recommendations should be done in required courses and these principles should be reinforced in clinical practice.

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Appendix A

- Test Sample Cover Letter**
- Test Sample Survey**
- Survey Sample Cover Letter**
- Final Draft Survey**

Cover Letter to Test Sample

(Name, Title)
(Organization)
(Address)

Dear (Name, Title)

I am a biology major at Ball State University working on an undergraduate honors fellowship with Dr. Jon Hendrix, Ball State's bioethics professor. We plan to survey the bioethics education received by a sample population of genetic counselors.

We would greatly appreciate your feedback on the effectiveness of our survey instrument in realizing our goal. Your suggestions will be used to make any modification on the final draft of this instrument.

Our goal in this research is to obtain qualitatively the training that our sample of genetic counselors have received and to ascertain their perceived needs with respect to bioethics education. We will compare these responses to data from our evaluation of currently available bioethics courses. From these analyses we could determine if there is a need to develop new curricular goals and objectives for the population surveyed.

Thank you for your cooperation.

Sincerely,

Manuela Wei, undergraduate honors fellow

Dr. Jon R. Hendrix, Director
HGABEL, Professor of Biology

**Genetics Counselors Bioethics Training Survey
Test Draft**

1) How many years have you been qualified to be certified as a genetic counselor? _____

2) How many years of service as a genetic counselor have you had? _____

3) From which geographic region did you receive your education or training. Note this listing was obtained from the geographic listing available in the NGCS Membership guide. (please check line)

- a. CT, ME, MA, NH, RI, VT
- b. DE, D.C., MD, NJ, NY, PA, VA, WV
- c. AL, FL, GA, KY, LA, MS, NC, SC, TN
- d. AR, IL, IN, IO, KS, MI, MN, MO, NE, OH, WI
- e. AZ, CO, MT, NM, ND, OK, SD, TX, UT, WY
- f. AK, CA, HI, ID, NV, OR, WA

4) In what type of location do you do most (over 50%) of your work?

- a. Metropolitan area- central city
- b. Metropolitan area- suburb
- c. Small city or town
- d. Rural

5) In what type of setting is most (over 50%) of your work done?

- a. University-based clinical genetics program
- b. Hospital-based clinical genetics program
- c. Independent medical genetics center
- d. Community health clinic
- e. Hospital owned or managed by a religious organization
- f. Other, please specify below

6) Approximately how many cases do you serve per year?

- | | |
|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> a. >1000 | <input type="checkbox"/> e. 100-299 |
| <input type="checkbox"/> b. 750-999 | <input type="checkbox"/> f. 50-99 |
| <input type="checkbox"/> c. 500-749 | <input type="checkbox"/> g. <50 |
| <input type="checkbox"/> d. 300-499 | |

7) Gender XY ___ XX ___

8) Is your personal faith statement important to your counseling work?

Yes No (If no, go to item 10)

For Likert scale items, please circle the number of your choice

9) If yes, how important? (please circle one).

Extremely Important	Very Important	Moderately Important	Slightly Important	Not at all Important
1	2	3	4	5

10) I feel my training and experience prepared me to deal with the ethical issues I encounter in my professional activities.

Strongly Agree 1 2 3 4 5 Strongly Disagree

11) I feel an undergraduate bioethics program *was/ would have been* (please circle one) helpful.

Strongly Agree 1 2 3 4 5 Strongly Disagree

12) I feel pre-service preparation is more important than in-service preparation.

Strongly Agree 1 2 3 4 5 Strongly Disagree

13) I feel it is important as a counselor to serve equally all who seek services.

Strongly Agree 1 2 3 4 5 Strongly Disagree

14) In my practice each year, I have had ___(specify below) cases dealing with *justice*. (eg. unbiased towards sex, race, religion, socio-economic status, sexual orientation.)

- | | |
|-----------|-----------|
| ___a. >10 | ___e. 1-3 |
| ___b. 8-9 | ___f. 0 |
| ___c. 6-7 | |
| ___d. 4-5 | |

15) I feel my bioethics training has prepared me in dealing with cases of *justice*.

Strongly Agree 1 2 3 4 5 Strongly Disagree

16) I feel it is important for me to enable my client to make an informed decision by providing necessary facts.

Strongly Agree 1 2 3 4 5 Strongly Disagree

17) In my yearly practice, I have had ___% cases dealing with *informed consent*.

- | | |
|----------------|-------------|
| ___a. 75%-100% | ___e. 1%-9% |
| ___b. 55%-74% | ___f. 0% |
| ___c. 35%-54% | |
| ___d. 10%-34% | |

18) I feel my bioethics training has prepared me in dealing with cases of **Informed consent**.
Strongly Agree 1 2 3 4 5 Strongly Disagree

19) I feel it is the responsibility of the counselor to maintain **confidential** in all cases any personal information received from the client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

20) In my practice each year, I have had ___% cases dealing with **confidentiality**.

- ___a. 75%-100%
- ___b. 55%-74%
- ___c. 35%-54%
- ___d. 10%-34%
- ___e. 1%-9%
- ___f. 0%

21) I feel my bioethics training has prepared me in dealing with cases of **confidentiality**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

22) I understand **non-maleficence** to be the obligation not to cause harm to my client. (e.g. exploitation of the client for personal advantage, profit, or interest)

Strongly Agree 1 2 3 4 5 Strongly Disagree

23) In my yearly practice, I have had ___ (specify below) cases dealing with the principle of **non-maleficence**.

- ___a. >10
- ___b. 8-9
- ___c. 6-7
- ___d. 4-6
- ___e. 1-3
- ___f. 0

24) I feel my bioethics training has prepared me in dealing with cases of **non-maleficence**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

25) I feel it is my obligation to always tell my client the whole truth, by providing all pertinent information about the diagnosis or case.

Strongly Agree 1 2 3 4 5 Strongly Disagree

26) In my practice each year I have had ___% cases dealing with **truth-telling**.

- ___a. 75%-100%
- ___b. 55%-74%
- ___c. 35%-54%
- ___d. 10%-34%
- ___e. 1%-9%
- ___f. 0%

27) I feel my bioethics training has prepared me in dealing with cases of **truth-telling**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

28) I feel it is imperative that I allow my client to make his/her own decision, after been provided all necessary information, free of coercion.

Strongly Agree 1 2 3 4 5 Strongly Disagree

29) In my yearly practice, I have had ___% cases dealing with **autonomy**.

- ___a. 75%-100% ___e. 1%-9%
___b. 55%-74% ___f. 0%
___c. 35%-54%
___d. 10%-34%

30) I feel my bioethics training has prepared me in dealing with cases of **autonomy**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

31) I think it is compulsory as a counselor to always do the greatest amount of good (**beneficence**) in consideration of my client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

32) In my practice each year, I have had ___% cases dealing with **beneficence**.

- ___a. 75%-100% ___e. 1%-9%
___b. 55%-74% ___f. 0%
___c. 35%-54%
___d. 10%-34%

33) I feel my bioethics training has prepared me in dealing with cases of **beneficence**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

34) I feel it is important to avoid being **paternalistic** when exploring alternate choices with my client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

35) I had ___% cases per year dealing with **paternalism**.

- ___a. 75%-100% ___e. 1%-9%
___b. 55%-74% ___f. 0%
___c. 35%-54%
___d. 10%-34%

36) I feel my bioethics training has prepared me in dealing with cases of **paternalism**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

37) I feel it is important that I always act with *fidelity* (strict observance of promises and duties) in my role as a counselor.

Strongly Agree 1 2 3 4 5 Strongly Disagree

38) In my yearly practice, I have had ___% cases with *fidelity*.

- ___a. 75%-100% ___e. 1%-9%
- ___b. 55%-74% ___f. 0%
- ___c. 35%-54%
- ___d. 10%-34%

39) I feel my bioethics training has adequately prepared me in dealing with cases of *fidelity*.

Strongly Agree 1 2 3 4 5 Strongly Disagree

40) In my practice I have encountered ___ cases in which I felt conflicts between my client's rights and the genetic health of societal members.

- ___a. >10 ___d. 1-3
- ___b. 8-10 ___e. <1
- ___c. 4-7

41) I feel my bioethics training has prepared me in dealing with conflicts of my client's rights and the genetic health of society.

Strongly Agree 1 2 3 4 5 Strongly Disagree

42) In my practice I have encountered ___% cases in which I felt conflicts between my client's rights and my personal beliefs.

- ___a. 75%-100% ___e. 1%-9%
- ___b. 55%-74% ___f. 0%
- ___c. 35%-54%
- ___d. 10%-34%

43) I feel my bioethics training has prepared me in dealing with conflicts between my client's rights and my personal beliefs.

Strongly Agree 1 2 3 4 5 Strongly Disagree

44) When I have encountered cases of client rights vs. my personal beliefs, I have been able to:

- ___a. accept my client's decision
- ___b. refer my client to another professional
- ___c. insist my client on accepting my views
- ___d. I have never encountered this situation

45) I feel my bioethics training has enabled me to deal with my answer to Item 44.

Strongly Agree 1 2 3 4 5 Strongly Disagree

The following items deal with your experience with in-service activities. Please answer according to the following statement...

" I have had the following experiences with in-service education programs within the past year."

	<u>Yes</u>	<u>No</u>	<u>How many in the past year?</u>				
46) attending post-graduate lectures or seminars.	1	2	1	2	3	4	>5
47) taking additional college-level bioethics courses.	1	2	1	2	3	4	>5
48) observing other genetic counselors.	1	2	1	2	3	4	>5
49) participate in practicums or internships.	1	2	1	2	3	4	>5
50) participate in bioethics forums.	1	2	1	2	3	4	>5
51) attend and participate in professional meetings.	1	2	1	2	3	4	>5
52) read current journals.	1	2	1	2	3	4	>5

Please answer the following question briefly.

53) My pre-service preparation in bioethics would have been better if...

Thank you for your time and effort in completing this survey. If you would like a copy of the results, please call 1-800-537-9604 after May 30, 1994.

Cover Letter to Survey Sample

(Name, Title)
(Organization)
(Address)

Dear (Name, Title)

The Human Genetics and Bioethics Education Laboratory at Ball State University has worked with undergraduate honors biology majors for the past 22 years. Many of these majors have chosen genetic counseling as their profession and are members of NSGC (National Society of Genetic Counselors). We want to serve these students in the best way possible. This is why we are seeking your responses to this short questionnaire. As curricula are modified your data will serve to influence its direction.

I am a biology major at Ball State University. I became concerned with bioethics as a result of my interest in genetic counseling and my work as an undergraduate honors fellow with Dr. Jon Hendrix, Ball State's bioethics professor. In an article by B.S. LeRoy in the Journal of Genetic Counselors, it was stated that out of 18 schools surveyed (the only ones with graduate genetic counseling training programs) , only four had a formal course in bioethics required for a degree in genetic counseling. Therefore, we have determined the need for our survey.

Our goal in this research is to obtain qualitatively the training that our sample of genetic counselors have received and to ascertain their perceived needs with respect to bioethics education. We will compare these responses to data of our evaluation of currently available bioethics courses. From these analyses we could determine if there would be a need to develop new curricular goals and objectives in accordance to the needs of the population surveyed.

Note that each survey is coded with a number in the right hand corner of the first page. These links to respondents will be destroyed after data are received. All data will be reported as grouped data and individual confidentiality is assured all respondents. Only the researchers will have access to the correlation list of number and counselor name.

Thanking you in advance.

Manuela Wei, undergraduate honors fellow

Dr. Jon R. Hendrix, Director HGABEL,
Professor of Biology

**Genetics Counselors Bioethics Training Survey
Final Draft**

- 1) How many years have you been qualified to be certified as a genetic counselor? _____
- 2) How many years of service as a genetic counselor have you had? _____
- 3) From which geographic region did you receive your education or training. Note this listing was obtained from the geographic listing available in the NGCS Membership guide. (please check the appropriate line)
- a. CT, ME, MA, NH, RI, VT
 - b. DE, D.C., MD, NJ, NY, PA, VA, WV
 - c. AL, FL, GA, KY, LA, MS, NC, SC, TN
 - d. AR, IL, IN, IO, KS, MI, MN, MO, NE, OH, WI
 - e. AZ, CO, MT, NM, ND, OK, SD, TX, UT, WY
 - f. AK, CA, HI, ID, NV, OR, WA
 - g. Other, please specify _____

- 4) In what type of location do you do most (over 50%) of your work?
- a. Metropolitan Area- central city
 - b. Metropolitan Area- suburb
 - c. Small city or town
 - d. Rural

- 5) In what type of setting is most (over 50%) of your work done?
- a. University-based clinical genetics program
 - b. Hospital-based clinical genetics program, hospital owned or managed by a religious organization
 - c. Independent medical genetics center
 - d. Community health clinic
 - e. Other, please specify below
-

- 6) Approximately how many cases do you serve per year?
- | | |
|-------------------------------------|-------------------------------------|
| <input type="checkbox"/> a. > 1000 | <input type="checkbox"/> e. 100-299 |
| <input type="checkbox"/> b. 750-999 | <input type="checkbox"/> f. 50-99 |
| <input type="checkbox"/> c. 500-749 | <input type="checkbox"/> g. < 50 |
| <input type="checkbox"/> d. 300-499 | |

7) Gender XY___ XX___

- 8) Is your personal faith statement (religious convictions) important to your counseling work?
 Yes No (If no, go to item 10)

For Likert scale items, please circle the number of your choice

- 9) If yes, to what degree does this influence my ability to counsel my clients. (please circle one).
Strongly Influence 1 2 3 4 5 No Influence

- 10) I feel my training and experience prepared me to deal with the ethical issues I encounter in my professional activities.
Strongly Agree 1 2 3 4 5 Strongly Disagree

- 11) I feel an undergraduate bioethics program *was/ would have been* (please circle one) helpful.
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 12) I feel pre-service preparation (before I began practicing as a genetic counselor) is more important than in-service preparation(experience I have encountered while counseling.)
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 13) I feel it is important as a counselor to abide by the principle of justice and serve equally all who seek services.
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 14) In my practice each year, I have had ___(specify below) cases dealing with problems of justice. (e.g.. the fair treatment of my clients by being unbiased towards sex, race, religion, socio-economic status, sexual orientation.)
 ___a. >10 ___e. 1-3
 ___b. 8-9 ___f. 0
 ___c. 6-7
 ___d. 4-5
- 15) I feel my bioethics training has prepared me in dealing with cases of justice with respect to patient contact.
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 16) I feel it is important as a counselor to act justly when counseling, by obeying the law.
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 17) In my yearly practice, I have had ___(specify below) cases dealing with problems of legal justice. (e.g. lawsuits)
 ___a. >10 ___e. 1-3
 ___b. 8-9 ___f. 0
 ___c. 6-7
 ___d. 4-5
- 18) I feel my bioethics training has prepared me in dealing with cases of justice with respect to the law.
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 19) I feel it is important for me to enable my client to make an informed decision by providing necessary facts.(informed consent)
Strongly Agree 1 2 3 4 5 Strongly Disagree
- 20) In my yearly practice, I have had ___% cases in which I have encountered the issue of informed consent.
 ___a. 75%-100% ___e. 1%-9%
 ___b. 55%-74% ___f. 0%
 ___c. 35%-54%
 ___d. 10%-34%
- 21) I feel my bioethics training has prepared me in dealing with cases of informed consent.
Strongly Agree 1 2 3 4 5 Strongly Disagree

22) I feel it is the responsibility of the counselor to maintain **confidential** in all cases any personal information received from the client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

23) In my practice each year, I have had ___% cases dealing with problems of **confidentiality**.

- ___a. 75%-100% ___e. 1%-9%
- ___b. 55%-74% ___f. 0%
- ___c. 35%-54%
- ___d. 10%-34%

24) I feel my bioethics training has prepared me in dealing with cases of **confidentiality** with respect to releasing documented information. (e.g. medical records, test results) or any information disclosed to me by my client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

25) I understand **non-maleficence** to be the obligation not to cause harm to my client. (e.g. exploitation of the client for personal advantage, profit, or interest)

Strongly Agree 1 2 3 4 5 Strongly Disagree

26) In my yearly practice, I have had ___ (specify below) cases dealing with the principle of **non-maleficence**.

- ___a. >10 ___e. 1-3
- ___b. 8-9 ___f. 0
- ___c. 6-7
- ___d. 4-6

27) I feel my bioethics training has prepared me in dealing with cases of **non-maleficence**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

28) I feel it is my obligation to always tell my client the whole truth, by providing all pertinent information about the diagnosis or case.

Strongly Agree 1 2 3 4 5 Strongly Disagree

29) In my practice each year I have had ___% cases dealing with problems of **truth-telling**.

- ___a. 75%-100% ___e. 1%-9%
- ___b. 55%-74% ___f. 0%
- ___c. 35%-54%
- ___d. 10%-34%

30) I feel my bioethics training has prepared me in dealing with cases of **truth-telling**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

31) I feel it is imperative that I allow my client to make his/her own decision, after been provided all necessary information, free of coercion.

Strongly Agree 1 2 3 4 5 Strongly Disagree

32) In my yearly practice, I have had ___% cases dealing with **autonomy** in which the client was not directed by others in making a decision.

- a. 75%-100%
- b. 55%-74%
- c. 35%-54%
- d. 10%-34%
- e. 1%-9%
- f. 0%

33) I feel my bioethics training has prepared me in dealing with cases of **autonomy**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

34) I think it is compulsory as a counselor to always do the greatest amount of good (**beneficence**) in consideration of my client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

35) In my practice each year, I have had ___% cases dealing with **beneficence**.

- a. 75%-100%
- b. 55%-74%
- c. 35%-54%
- d. 10%-34%
- e. 1%-9%
- f. 0%

36) I feel my bioethics training has prepared me in dealing with cases of **beneficence**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

37) I feel it is important to avoid being **paternalistic** (restricting the liberty of my client without their consent, or justifying such actions as to prevent some harm or to produce some benefit) when exploring alternate choices with my client.

Strongly Agree 1 2 3 4 5 Strongly Disagree

38) I had ___% cases per year dealing with **paternalism**.

- a. 75%-100%
- b. 55%-74%
- c. 35%-54%
- d. 10%-34%
- e. 1%-9%
- f. 0%

39) I feel my bioethics training has prepared me in dealing with cases of **paternalism**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

40) I feel it is important that I always act with **fidelity** (strict observance of promises and duties) in my role as a counselor.

Strongly Agree 1 2 3 4 5 Strongly Disagree

41) In my yearly practice, I have had ___% cases with **fidelity**.

- a. 75%-100%
- b. 55%-74%
- c. 35%-54%
- d. 10%-34%
- e. 1%-9%
- f. 0%

42) I feel my bioethics training has adequately prepared me in dealing with cases of **fidelity**.

Strongly Agree 1 2 3 4 5 Strongly Disagree

43) In my practice I have encountered ___ cases in which I felt conflicts between my client's rights and the genetic health of societal members.

- ___ a. >10 ___ d. 1-3
 ___ b. 8-10 ___ e. <1
 ___ c. 4-7

44) I feel my bioethics training has prepared me in dealing with conflicts of my client's rights and the genetic health of society.

Strongly Agree 1 2 3 4 5 Strongly Disagree

45) In my practice I have encountered ___% cases in which I felt conflicts between my client's rights and my personal beliefs.

- ___ a. 75%-100% ___ e. 1%-9%
 ___ b. 55%-74% ___ f. 0%
 ___ c. 35%-74%
 ___ d. 10%-34%

46) When I have encountered cases of client rights vs. my personal beliefs, I have been able to...

- ___ a. accept my client's decision
 ___ b. refer my client to another professional
 ___ c. insist my client on accepting my views
 ___ d. I have never encountered this situation

47) I feel my bioethics training has prepared enabled me to deal with my answer to Item 46.

Strongly Agree 1 2 3 4 5 Strongly Disagree

The following items deal with your experience with in-service activities. Please answer according to the following statement...

" I have had the following experiences with in-service education programs within the past year."

	<u>Yes</u>	<u>No</u>	<u>If yes, how many in the past year ?</u>				
48) attending post-graduate lecture or seminars.	1	2	1	2	3	4	>5
49) taking additional college-Level bioethics courses.	1	2	1	2	3	4	>5
50) observing other genetic counseling	1	2	1	2	3	4	>5
51) participate in practicums internships.	1	2	1	2	3	4	>5
52) participate in bioethics forums	1	2	1	2	3	4	>5
53) attend and participate in professional meeting	1	2	1	2	3	4	>5
54) read current journals	1	2	1	2	3	4	>5

GO ON TO NEXT PAGE!

Please answer the following question briefly.
55) My pre-service preparation in bioethics would have been better if...

Thank you for your time and effort in completing this survey. If you would like a copy of the results, please call 1-800-537-9604 after May 30, 1994.

Appendix B

- Syllabus Request Letter**
- Follow-up Postcards**

Syllabus Request Letter

Director of Genetic Counseling Graduate Program
(Organization)
(Address)

(Date)

Dear Director of Genetic Counseling Graduate Program,

I am a biology major at Ball State University currently working on an undergraduate honors fellowship with Dr. Jon Hendrix, Ball State's Bioethics professor and Director of the Human Genetics and Bioethics Education Laboratory.

Our goal in this research is to explore the content of bioethics courses which master's level genetic counselors take. This fall we sent out surveys to determine the training our sample of genetic counselors have received and to ascertain their perceived needs in respect to bioethics education. We will use these data to explore the content of currently available bioethics courses. From these data analyses we could determine if there is a need to develop new curricular goals and objectives for our own course and for others who may wish to develop a bioethics course that would serve this population.

We would greatly appreciate a detailed course syllabus of your bioethics course. Our data will be reported as grouped data and will not identify specific institutions. We would sincerely appreciate a prompt response as Manuela's honors thesis is due in April 1994.

Thank you for your cooperation.

Sincerely,

Manuela Wei, undergraduate honors fellow

Dr. Jon R. Hendrix, Director HGABEL
Dept. of Biology
Ball State University
Muncie, IN 47306

A Friendly Reminder



Please help me by responding and returning the bioethics education survey. My thesis is due in April and I do so need your help.



Happy New Year,



Manuela Wei
Biology Department
Ball State University
Muncie, IN 47306



A Friendly Reminder



Please Help me by sending a syllabus of your bioethics course taken by master's degree genetic counselling students, or materials related to bioethics training received by these individuals. Part of my study depends on these materials and my thesis is due in April.



Thank you,



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