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Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives

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New technologies available in the field of medical genetics have increased the importance of responsible ethical decision-making among genetic counselors. A 1985 national survey of M.D. and Ph.D. genetic counselors assessed ethical attitudes using case scenarios designed to simulate dilemmas faced in genetic counseling (Wertz and Fletcher, 1988b). The current study focuses on attitudes of M.S. genetic counselors using similar scenarios, allowing for effective comparisons. M.S. counselors were more willing than M.D. and Ph.D. counselors to maintain patient confidentiality when screening for Huntington's Disease and occupational diseases, and a greater number would agree to counsel patients pursuing prenatal testing for sex selection. A majority of M.S. counselors would disclose an XY karyotype to a phenotypically female patient. M.S. counselors reasoned that respect for patient autonomy and patient confidentiality justified their decisions in many cases. The importance of these principles is discussed and questioned.

KEY WORDS: ethical issues; medical ethics; genetic screening; genetic counseling; ethics.

INTRODUCTION

Rapid growth in the area of medical genetics is providing a wealth of new options for dealing with genetic disease. These technologic advances

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often pose unique and significant ethical dilemmas which must be resolved by providers of genetic services and individuals who receive those services, as well as society in general. Reproductive options such as artificial insemination by donor, genetic screening, *in vitro* fertilization, sex selection via prenatal testing, surrogate motherhood, fetal tissue transplantation, and gene therapy have generated considerable ethical concerns. As genetic counselors relay important genetic and reproductive information to families at risk and to the public, they often play an important role in the way these ethical issues are understood and acted upon.

Major ethical principles which govern the attitudes and actions of counselors include (1) respect for patient autonomy, or the patient's right to information and his/her right to make his/her own decisions, (2) nonmaleficence, which is defined by Fletcher *et al.* (1985) as one's "duty to minimize or prevent the infliction of harm on individuals and families," (3) beneficence, or taking action to help benefit others and prevent harm, and (4) justice, which requires that services be distributed fairly to those in need. Other moral rules include veracity, the duty to disclose information or to be truthful, and respect for patient confidentiality.

Nondirective counseling, a hallmark of the genetics profession, is largely in accordance with the principle of respect for patient autonomy and incorporates the other ethical principles as well. Despite an overall respect for patient autonomy and the value of nondirective counseling within the genetics community, it is virtually impossible to be completely nondirective, especially when the counselor has a particular bias. Factors such as order of presentation of information, amount of time spent counseling about an option, voice inflection, and body language can all influence a patient's perception of information.

Three groups of professionals currently consider themselves genetic counselors: M.D. clinical geneticists, Ph.D. medical geneticists, and M.S. genetic counselors. Although two thorough studies were done on attitudes of genetic counselors in the United States, these surveys were directed at M.D. and Ph.D. counselors (Wertz and Fletcher, 1988b; Sorenson *et al.,* 1981). Wertz and Fletcher (1988a) omitted M.S. counselors because there were few outside of the United States and Canada, and their survey was intended to be comparable across nations.

In the present study, M.S. genetic counselors were surveyed using case scenarios designed to simulate ethical decision-making. Many of these cases were identical to those presented to M.D.s and Ph.D.s in 1985 by Wertz and Fletcher (1988a,b). Identical cases were used in order to facilitate effective comparisons between the two groups. It was expected that a survey of M.S. counselors would yield significantly different responses to some ethical questions given that (1) they counsel patients more frequently, (2) a

larger percentage of the M.S. counselor population is female, and (3) M.S. counselors have more training in counseling (Sorenson *et al.,* 1981).

SUBJECTS AND METHODS

The study population included M.S. genetic counselors with full membership status in the National Society of Genetic Counselors (NSGC). Genetic counselors with equivalent degrees, who were considered equally trained for an M.S. position, were also included; most respondents in this category had an M.S. in human genetics or nursing. Ph.D. and M.D. respondents were not included in the analysis (except two respondents who also held M.S. degrees in genetic counseling) to prevent overlap with the Wertz and Fletcher (1988b) results.

Counselors were asked to respond to a survey composed of 22 case scenarios designed to challenge ethical principles applied in clinical genetics. Seventeen cases were identical to those presented in the 1985 Wertz and Fletcher survey. Some cases from the 1985 study were not included because their results (Wertz and Fletcher, 1988b) showed an overwhelming consensus, and a different result would not be expected with our study population. Five new scenarios were added to collect information on recently developed technologies.

As with the Wertz and Fletcher survey, respondents were asked to choose their most likely response to a clinical situation and state why it was chosen on the basis of ethical reasoning rather than personal, technical, or legal justifications. Responses were entirely voluntary and were returned anonymously by the counselor.

Chi-square analysis was used to investigate significant differences in counselor responses to vignettes based on their sex, age, geographic region of employment, training in ethics, number of years they had been counseling, and religious preference. Final results were then compared to those of the 1985 survey sent by Wertz and Fletcher based on published data.

RESULTS

Demographics

Of the 543 counselors surveyed, 199 responded (36.6%) (Table I). Eighty-three percent of respondents held an M.S. in genetic counseling and 11.6% had another type of M.S., most commonly in human genetics or nursing. Respondents reported seeing an average of 11 patients per week and spent an average of 16 hours per week in counseling. The population was predominantly female (93.5%) and white (97.5%). About half of counselors

Table I. Demographics

	Percent responding	
Gender	F = 93.5	M = 6.5
Race	White = 97.5 Black = 0.5	Other = 1.5 Hispanic = 0.5
Age	Mean = 34.3	Median = 32
Marital status	Married = 62.8 Widowed = 1.5	Single = 28.6 Divorced = 6.5
Number of children	None = 53.5	46.5% = Mean of 1.8
Religion	Protestant = 37.7 None = 18.1 Other = 5.5	Jewish = 22.1 Catholic = 16.6
Education	M.S. genetic counseling = 83.4 M.S. (other) = 11.6 Registered nurse = 1.0	Other = 4.0
Certification	Board certified = 70.7	Board eligible = 27.3
Counseling training	Didactic = 92.4	Clinical = 96.4
Average number of patients per week = 11		
Average number of hours spent counseling per week = 16		
Instruction in ethics in genetic counseling training = 53.8		

were married (62.8%) and had children (46.5%). Most counselors were Protestant (37.7%), Jewish (22.1%), or Catholic (16.6%), but less than half (43.9%) considered themselves religiously active (Table I).

Most counselors reported having had both didactic (92.4%) and clinical (96.4%) training in counseling, in addition to training in medical genetics. Over half (53.8%) also said they had received formal instruction in ethics during their genetic counseling training.

Clinical Case Responses

Disclosure Issues

One case involved a child who had translocation Down Syndrome. Counselors were asked if they would tell the parents which parent carried the translocation and under what circumstances they would reveal this information (Table II). Though closely divided, more counselors felt that the parents had a right to confidentiality and would not reveal the carrier unless the parents specifically wished to know. Interestingly, M.S. counselors with training in ethics tended to respect patient autonomy more often by not disclosing the information unless asked (62.3%), while those without training in ethics tended to favor disclosing without parental permission

Table II. Issues Involving Full Disclosure vs. Nonmaleficence

	Percent responding					
	Disclose		Disclose only if asked		Not disclose	
Scenario	USC[a]	W & F[b]	USC	W & F	USC	W & F
Parental translocation	43.1	62	56.9	38	0	0
Nonpaternity	1.5	6	N/A		98.5	94
XY female	73.2	64	N/A		26.8	36

[a]USC = University of South Carolina 1989 survey of M.S. counselors.
[b]W & F = Wertz and Fletcher 1985 survey of M.D. and Ph.D. counselors in the United States.

(51.7%). This difference was significant at $p = .05$. In contrast to the overall M.S. counselor response, a majority of M.D. and Ph.D. geneticists felt the information should be given, despite parental wishes, perhaps so that other family members might benefit from the information.

Counselors in both studies were more consistent in maintaining the mother's confidentiality when nonpaternity is fortuitously discovered by DNA studies, as described in another case scenario. Most M.S. counselors chose to tell the mother alone. They felt justified because they were preserving patient confidentiality and not endangering the family unit/marriage.

More sensitive situations, such as telling an infertility patient that she has an XY genotype, led to greater disparity. In general, M.S. genetic counselors felt more obligated to disclose this information than respondents in the Wertz and Fletcher study. Sixty-two M.S. counselors reasoned that the patient had a right to know the cause of her infertility. A few believed that telling her in a sensitive and professional way may avoid the harm she could experience if she found out from a less sensitive source later in life. Most counselors would offer support and follow-up for the patient. Not shown in the table, it is interesting to note that M.S. counselors in eastern states, excluding the New England region, were less likely ($p = .009$) to disclose XY genotype information than counselors in other areas of the United States.

Prenatal Diagnosis

Genetic professionals have long been divided about the issue of prenatal diagnosis for sex selection (Table III). M.S. counselors were more willing than M.D. and Ph.D. respondents to counsel for sex selection but

Table III. Controversial Indications for Prenatal Diagnosis

	Percent responding					
	Perform		Refer		Refuse	
Scenario	USC[a]	W & F[b]	USC	W & F	USC	W & F
Parents oppose abortion	100	96	0	0	0	4
Maternal anxiety	95.5	78	3.5	11	1	11
Sex selection	38.3	34	43.4	28	18.3	38
Fetal tissue use	33.0	N/A	41.0	N/A	26.1	N/A

[a]USC = University of South Carolina 1989 survey of M.S. counselors.
[b]W & F = Wertz and Fletcher 1985 survey of M.D. and Ph.D. counselors in the United States.

were still largely divided in their response. Most counselors (61.7%) would not grant the couple's request, but a large number (43.4%) would refer them to another center. Many counselors disagreed with sex selection because it is not a medical indication for testing and because prenatal diagnostic services are a limited resource. Others found it "morally repugnant" and felt they had an obligation to respect their own moral values. Of those counselors who would grant the patient's request or refer, many reasoned that the patient has a right to choose and felt it their duty to respect patient autonomy.

The use of prenatal diagnosis for purposes such as fetal tissue use, i.e., to help relieve Parkinson's Disease in a relative, was also controversial and gained no consensus. Most counselors would refuse to counsel a patient for this indication because they felt they had to protect the rights of the fetus, or because this was deemed an inappropriate use of a medical technology which is also a limited resource. Other counselors felt the patient has a right to autonomy or choice, and would continue to offer testing or refer. Jewish counselors and counselors with no religious affiliation were more inclined ($p = .002$) to counsel these patients than counselors from other religious backgrounds.

M.S. respondents felt that patient autonomy and the patient's right to know fetal status outweighed the principle of justice when asked if they felt prenatal testing should be available for maternal anxiety or for parents who would not abort an abnormal fetus.

Another finding, not included in the table, showed that virtually all counselors would be nondirective when counseling parents about low-burden chromosome disorders (XO = 96.4% and XYY = 95.4%) detected prenatally. Twenty-three percent of respondents would be nondirective, but

Table IV. Disclosure of Huntington's Disease to Relatives at Risk

	Percent responding			
	Patient refuses to tell relatives at risk		Presymptomatic test	
	USC[a]	W & F[b]	USC	W & F
Respect confidentiality	59.4	39	75.3	56
Disclose	14.5	24	13.4	24
Disclose if asked	19.8	29	11.3	20
Refer	6.3	8	N/A	

[a]USC = University of South Carolina 1989 survey of M.S. counselors.
[b]W & F = Wertz and Fletcher 1985 survey of M.D. and Ph.D. counselors in the United States.

also describe the emotional difficulties associated with terminating a pregnancy. These results agreed strongly with those of Wertz and Fletcher in which 90% and 95% of respondents would be nondirective about fetal findings of XO and XYY, respectively. Twenty-four percent would describe the difficulties of termination.

Genetic Screening

Two scenarios involved the disclosure of Huntington's Disease to relatives at risk. In the first case, a patient who is clinically diagnosed with Huntington's Disease does not want the diagnosis and relevant genetic information to be revealed to family members at risk. A majority of M.S. counselors would respect patient confidentiality, fewer M.D. and Ph.D. counselors would. Counselors felt more strongly that confidentiality should be maintained if a patient is ascertained through potentially routine presymptomatic DNA testing (Table IV). In general, M.S. counselors would maintain patient confidentiality under most circumstances, including not telling the patient's spouse (Table V).

With regard to occupational screening for diseases such as alpha-1-antitrypsin, most counselors (92.8%) felt that screening should be voluntary. These results are higher than those of Wertz and Fletcher in which 77% of their sample felt it should be voluntary. Only 5.3% of respondents would give either the employer or an insurer the results without patient consent; these results are somewhat lower than percentages quoted by Wertz and Fletcher. More M.S. counselors (29.3%) would allow the worker's physician to have access to the results without consent. Respondents reasoned that

Table V. Access to Results of Presymptomatic Testing for Huntington's Disease

	Percent responding		
	Respect confidentiality[a]	Disclose if asked	Disclose (even if not asked)
Patient	—	86.9	13.2
Relatives at risk	75.3	11.3	13.4
Spouse	77.1	5.3	17.6
Insurance companies	98.4	1.6	0
Employer	99.5	0.5	0

[a] Respect confidentiality includes respondents who said they would disclose only if the patient approves and those who would not disclose, regardless.

the physician would aid in the worker's understanding of the implications of the results in reference to his health.

Reproductive Technologies

As expected, results showed that counselors would be essentially nondirective in presenting options to patients, whether they pertained to reproduction options or gene therapy. More than 80% of M.S. counselors would present almost every reproductive option available, including adoption, artificial insemination by donor (AID), *in vitro* fertilization (IVF), contraception, sterilization, and taking their chances. The only exception was that of surrogacy, which would only be presented by 67% of M.S. counselors. These results are fairly consistent with the Wertz and Fletcher U.S. data, and slightly higher than their international results (Fig. 1).

Analysis of the responses concerning surrogacy revealed a significant difference in the religion of M.S. counselors regarding offering surrogacy as an option. Catholic counselors would tend not to discuss surrogacy, or would discuss it only if asked ($p = .001$). They were also less inclined to discuss IVF ($p = .004$).

M.S. genetic counselors almost unanimously agreed that reproductive options should be made available to everyone, including single women and lesbians. Over 95% would discuss adoption and AID with both, and slightly fewer, over 86%, would offer IVF. Fewer respondents would offer IVF because of limited resources and the expense to the patient.

Assuming that gene therapy was available and medically acceptable, most M.S. counselors would at least mention both somatic cell and germ line therapy. In fact, 15.5% of counselors would even encourage somatic cell therapy since it may offer a cure without affecting future generations.

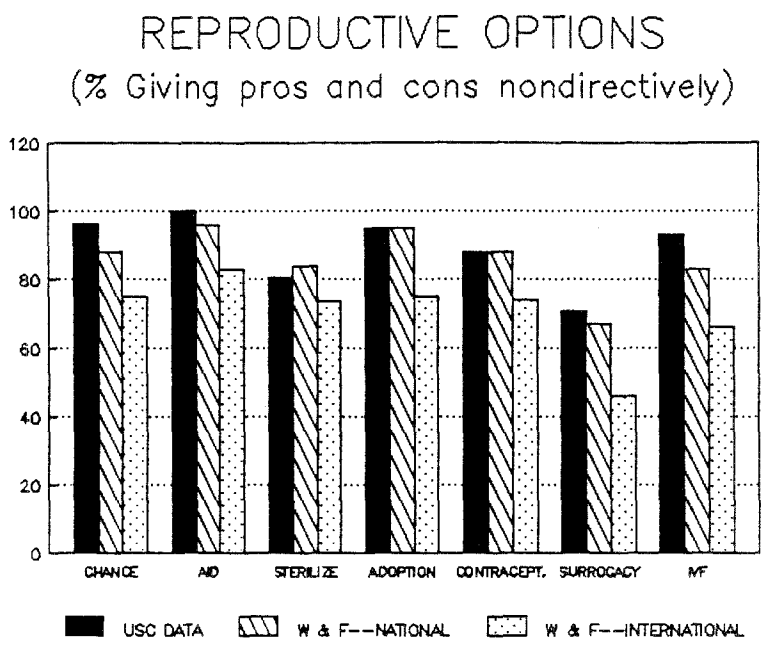

Fig. 1. Counselors were asked if and how they would present all reproductive options. W & F = Wertz and Fletcher 1985 survey results. CHANCE, taking their chances; AID, artificial insemination by donor; STERILIZE, vasectomy or tubal ligation; ADOPTION, adoption; CONTRACEPT., contraception; SURROGACY, surrogate motherhood; and IVF, donor egg and *in vitro* fertilization.

A few counselors (4.8%) would be more conservative and would not mention or would discourage germ line gene therapy. Even fewer counselors (3.7%) would encourage it since it would yield a permanent change in the DNA of future generations.

DISCUSSION

A strong consensus exists among M.S. genetic counselors concerning their response to important ethical dilemmas encountered within the profession. Although results from this survey suggest that M.S. counselor attitudes are somewhat more patient-oriented, their responses correspond well with those of M.D. and Ph.D. counselors.

A few important exceptions are worth noting. A majority of medical geneticists would reveal, without being asked, which parent is a translocation carrier. The results found in this study showed a majority of counselors

would not disclose unless the parents wanted to know. Screening results would also be disclosed to relatives at risk or other third parties more often by medical geneticists. Although medical geneticists favored patient confidentiality in these situations, it was to a lesser degree than M.S. counselors. This indicates that the Wertz and Fletcher population considered the rights of others to weigh more heavily in this situation than did M.S. genetic counselors, who would more consistently favor patient autonomy and confidentiality.

Reasons for the differences between M.S. and M.D. or Ph.D. responses could be related to differences in education, such as training in ethics or counseling. Sorenson *et al.* (1981) reported that only a minority of M.D. and Ph.D. counselors in their study received training in counseling, whereas M.S. counselors are trained specifically in counseling. Training in counseling and ethics may enable counselors to be more aware of the emotional impact of their decisions on all parties involved, i.e., the patient, family members, or society. And, with counseling training, a caregiver may be better equipped to reveal sensitive information, such as in the case of the XY female. Perhaps medical school programs should include training in counseling and genetic ethics thus enhancing the ability of physicians to deal with ethical dilemmas and patients in crisis.

Differences in response may also be affected by more abstract issues such as the number of patients counseled per week or a change of society's attitudes toward screening since administration of the Wertz and Fletcher survey. Wertz and Fletcher report that 55% of their respondents counsel five or fewer patients per week. M.S. counselors averaged 11 patients per week. Since M.S. counselors see a greater number of patients, they should have a better understanding of the emotional needs and responses of patients who are faced with difficult decisions or information. This enhanced understanding should lend important insight to counselors faced with ethical dilemmas involving patient care.

Gender may also play an important role. Most M.S. counselors who responded were female (93.5%), whereas 65% of M.D. and Ph.D. respondents were male. Wertz and Fletcher found that more women than men would allow the use of prenatal diagnosis for sex selection and maternal anxiety. Our results agree with their conclusions because a higher percentage of M.S. counselors would not refuse couples desiring testing for these nonmedical indications. Gender differences between the two studies might also explain why more M.S. counselors would be nondirective in counseling for an XYY or XO fetus. Wertz and Fletcher found that fewer males would be nondirective in counseling for these situations.

The results of this survey indicate that M.S. genetic counselors, who have more training in counseling and spend more time with patients, have

stronger opinions about patient autonomy and the patient's right to choose. The principles of respect for patient autonomy and the patient's right to confidentiality were consistently noted as the ethical principles used to explain the choices that were made. Wertz and Fletcher also reported that the principle of autonomy dominated decision making in 59% of cases, followed by nonmaleficence in 20% (1989).

Despite the obvious consensus regarding respect for patient autonomy, several authors have recommended a more cautious use of this important principle. Childress (1990) suggests that "focusing narrowly on the principle of respect for autonomy can foster indifference." In addition, Wertz and Fletcher (1989) conclude from their international study that the welfare of the child or fetus counts for little and the welfare of society even less in comparison to the welfare of the patient or parent. They suggest that we "re-examine medical genetics' underlying values and . . . give attention to alternative value-systems that may emphasize beneficence and justice." Our results even more strongly confirm a dependence on the principle of autonomy, and therefore emphasize this need for more careful analysis of our ethical approaches to genetic issues.

Yarborough *et al.* (1989) emphasize the importance of the principle of beneficence within the genetic counseling framework. They suggest a method for balancing this significant principle with that of respect for patient autonomy without sacrificing nondirective ideals. As our knowledge of the human genome continues to expand, it will be of utmost importance to consider the value of the principle of beneficence and to reevaluate our current attitudes with respect to the various ethical principles.

Rapid technological progress in the field of genetics demands the moral and ethical attention of each genetic counselor and medical geneticist. As the link between genetic technology and the public, genetics professionals are in an ideal position to understand and influence the ethical impact of new technology on the individual and society. It is important that genetic counselors continue being patient advocates, but it is imperative, for the sake of our patients and society, that we take a thoughtful look at genetic technologies available now, and those that will be available in the near future, and that we play an active role in developing responsible ethical guidelines for their use.

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