Am. J. Hum. Genet. 42:592–600, 1988

Attitudes of Genetic Counselors: A Multinational Survey

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Summary

Of 1,053 medical geneticists in 18 nations, 677 (64%) returned questionnaires on their views on the importance of seven goals of genetic counseling, the appropriateness of five directive/nondirective approaches to counseling, and their choices of action in four situations involving directive/nondirective counseling. The majority (92%–94%) regarded nondirective approaches as appropriate; their views on both goals and approaches were similar to those reported in an earlier survey of 205 genetic counselors in the United States. In clinical situations involving presentation of reproductive options to carriers of disorders not diagnosable prenatally, 74%–85% would present contraception, sterilization, taking one's chances, artificial insemination donor (AID), or adoption as options even if not asked; 66% would present in vitro fertilization (IVF) with a donor egg; and 46% (67% in the United States) would present surrogate motherhood. In regard to three situations involving fetuses with low-burden disorders (Turner syndrome, XYY, and a possible small neural tube defect), 84%–88% would counsel nondirectively. Stepwise logistic regression analyses on professional and personal background variables showed that gender was related, cross-nationally, to self-reported directiveness in counseling, with men more likely than women to regard directive approaches as appropriate, more likely to give advice about fetuses with low-burden disorders, and more likely to present either IVF with donor egg or surrogate motherhood as options. Social and ethical implications of this widespread acceptance of nondirective counseling are discussed.

Introduction

Modern genetic counseling, as practiced in English-speaking countries, has generally pursued the goals described by Fraser in 1974, including helping clients "to understand their options and to choose the course of action which seems most appropriate to them in view of their risk and their family goals and act in accordance with that decision" (Fraser 1974). Counselors act as "decision facilitators," providing information without being directive. In a survey of 205 genetic counselors in the United States in 1979, Sorenson et al. (1981) found widespread consensus about objectives and approaches. Most counselors claimed that they proceeded on the basis of respect for the patient's autonomy in decision making; their stated approach was nondirective.

As yet, there has been no systematic study of genetic counseling on a cross-cultural basis. Fletcher et al. (1985) proposed that medical geneticists around the world would benefit from collective reflection on their preferred approaches. In response, we studied the degree of consensus and variation among medical geneticists worldwide, from different cultures, when they were presented with various counseling situations that posed ethical dilemmas. We summarize the responses of 677 medical geneticists in 18 nations to Sorenson's checklists of goals and approaches, and we also summarize their choices of action in four clinical case vignettes involving directive/nondirective counseling.

We anticipated that there would be worldwide consensus about counseling's objectives and approaches, partly because of deeply held beliefs about patient autonomy and partly because many medical geneticists receive some of their specialty training in the United States, Canada, or the United Kingdom.

Received July 22, 1987; revision received September 29, 1987.

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0002-9297/88/4204-0010$02.00

On the other hand, we expected that, for cultural or social reasons, counseling might follow a more directive course in some nations. The following is part of a larger study, currently in progress, on approaches to problems of moral choice in medical genetics in 18 nations (Fletcher et al. 1987).

Methods

Questionnaire Design

To identify the ethical problems most frequently encountered cross-nationally in the practice of medical genetics, one of us (J.C.F.) undertook field studies in 1984 at 25 genetic centers in 12 nations (Denmark, Federal Republic of Germany [FRG], France, Greece, Hungary, Italy, The Netherlands, Norway, Sweden, Switzerland, the United Kingdom, and the United States). Problems identified through the site visits became the basis for a survey questionnaire containing 14 clinical situations. Four of these specifically involved choices of directive or nondirective approaches in counseling. Respondents were asked *which* response in a fixed list of possible responses they would choose and *why,* in their own words, they would choose this particular course of action. Finally, there were questions about the importance or appropriateness of seven goals and five directive/nondirective approaches to counseling, using the wording of the Sorenson et al. (1981) survey.

The present paper focuses on geneticists' responses both to the questions about counseling goals and to the four case vignettes involving directive/nondirective counseling. The case vignettes were constructed as follows: The first involved presenting reproductive options to carriers of tuberous sclerosis, a dominant disorder not diagnosable prenatally. The question was phrased this way: "Evaluation of a child produces findings consistent with a diagnosis of tuberous sclerosis. Upon examining the parents, you find evidence that one is carrying the tuberous sclerosis gene, even though s/he is of normal intelligence. After a discussion of the risk of having another child with tuberous sclerosis who might be severely affected, the couple asks you whether recurrence of the disorder can be prevented. What course of action do you take with regard to EACH of the following options?" Options listed were adoption, AID, taking one's chances, contraception, tubal ligation, vasectomy, IVF with a donor egg, and insemination of a surrogate mother with the husband's sperm. The courses of action listed were (1) advise the clients to do this, (2) advise the clients *not* to do this, (3) explain that this is a possibility, without giving any advice, (4) explain that this is a possibility and describe the risks and potential problems involved, (5) not discuss this, and (6) discuss this only if the clients ask you about it. Choice number 4 expresses nondirective and informative counseling to the fullest extent, but number 3 can also be considered nondirective counseling, and we have reported it as such. Choices 5 and 6 represent forms of directiveness, in that options are not openly set forth.

The other three case vignettes dealt with counseling about fetuses with disorders commonly viewed as having a low burden: e.g., Turner syndrome, XYY, and a possible small neural tube defect (NTD). The case of the possible small NTD was phrased as follows:

"Maternal serum alpha-fetoprotein has been elevated in your patient on two occasions, but level II ultrasound discloses no abnormality, despite careful examination of the fetal head, spine, abdomen, and kidneys. The fetal karyotype is normal. Amniotic alpha-fetoprotein is elevated and acetylcholinesterase is borderline. These results raise the possibility of a small neural tube defect. What do you tell the parents?"

The questionnaire was pilot-tested twice on 11 and 10 geneticists, respectively, from the United States and Canada and revised after each trial. The questionnaires took ~2 h to complete. We asked respondents to set the questionnaires aside for a day after completing the first half, so that they might approach the second half freshly. Questionnaires were answered anonymously.

Study Participants

We selected geneticists who held an M.D., Ph.D., or equivalent degree and who were engaged in delivering or administering genetic services (testing, counseling, prenatal diagnosis, and/or laboratory work). Although in some countries (notably the United States) counseling is sometimes done by specially trained persons who do not hold a doctorate, we decided to omit these persons, to control for consistency of training across the entire sample. We concentrated on those with terminal degrees because they are most likely to affect policies about counseling in their own nations, even though 10% did no counseling themselves.

The criteria for choosing the countries for final study were (*a*) 10 or more practicing geneticists, (*b*)

Table 1

Participating Nations

Country	No. of Persons Asked to Participate	No. of Persons Responding (%)
Australia	14	12 (86)
Brazil	51	32 (63)
Canada	73	47 (64)
Denmark	28	15 (58)
FRG	55	47 (85)
France	35	17 (49)
GDR	25	21 (80)
Greece	11	7 (64)
Hungary	18	15 (83)
India	40	27 (67)
Israel	17	15 (88)
Italy	26	11 (42)
Japan	74	51 (69)
Norway	10	6 (60)
Sweden	26	21 (81)
Switzerland	10	5 (50)
United Kingdom	50	33 (66)
United States	490	295 (60)
Total	1,053	677 (64)

geographical and cultural distribution, and (*c*) the presence of a medical geneticist willing to distribute and collect questionnaires and to coauthor, with a specialist in medical ethics, a chapter in our future monograph, *Ethics and Human Genetics.* In each country, including the United States, our contact geneticists tried to include all qualified medical geneticists in the survey. Lists were compiled from certifying boards, genetics centers, and the National Foundation–March of Dimes *International Directory of Genetic Services.*

Of the 1,053 geneticists asked to participate, 677 (64%) returned completed questionnaires by the close of the study in February 1987 (table 1). Eighty-seven percent of these answered all parts of the questionnaires, including a statement in their own words as to why they would choose a particular course of action. Eighty-one percent of the respondents held M.D.s (including 45% who were pediatricians), 16% held Ph.D.s, and 3% held other degrees. They had a median of 14 years in the practice of genetics; 84% were members of their national genetics society; and 77% were board certified in countries where certification in genetics was possible (Canada, Hungary, the United Kingdom, and the United States). Respondents spent a weekly median of 4 h counseling patients, 6 h in administrative work, 5 h reading professional journals, and 4 h in laboratory work. In all, 10% did no counseling, 20% counseled one or two patients per week; 25% counseled two to five, 18% counseled six to nine, and 26% counseled 10 or more patients per week. Sixty-five percent were male, and 82% were married, with a median of 1.5 children. Religious backgrounds were 40% Protestant, 18% Catholic, 17% Jewish, 12% none, 5% Buddhist, 4% Hindu, and 4% other. As a whole, they were nonpracticing, attending a median of one religious observance a year. Forty-nine percent characterized themselves as politically liberal, 15% as conservative, and 36% as both equally. In the United States, a comparison between 274 respondents and 208 nonrespondents listed in the 1986 combined *Membership Directory* of the Genetics Society of America, American Society of Human Genetics, and American Board of Medical Genetics revealed no statistically significant differences between respondents and nonrespondents in type of degree, gender, geographical area, or subspecialty. Qualitative responses, including the responders' anticipation of consequences of their choices, were coded and entered into a Statistical Package for the Social Sciences (SPSS-X) program.

The criterion for consensus was one frequently used in legislative processes, in the absence of an accepted scientific criterion for consensus—that is, the three-quarters rule (three-quarters of the respondents in each of three-quarters of the countries surveyed) defined a strong consensus. This method allows representation to each country. If we had used percentages of the total number of responses, the United States, with 44% of all respondents, would have been disproportionately represented.

To see whether geneticists' responses were consistently related to factors in their professional or personal backgrounds, over and above their nationality, we entered all sociodemographic data—including degree, age, gender, years of experience, hours per week in genetics, patients per week, subspecialty, political inclination, religious background, religiosity, and nation—into a stepwise logistic regression, with questionnaire responses (e.g., importance of a counseling goal) as the dependent variable. This method orders each personal and professional background variable in terms of its strength of association with the dependent variable, (e.g., importance of counseling goal) while controlling for other statistically significant variables. In addition, this analysis provides an estimate of the odds ratio, that is, the odds that a genet-

Table 2

Goals of Counseling: % of 677 Respondents Believing Goal Important (Absolutely Essential)

	GOAL						
COUNTRY	Help Patients Understand Their Options So They Can Make Informed Decisions	Help Patients Cope with Genetic Problems	Remove or Lessen Guilt or Anxiety	Help Patients Achieve Parenting Goals	Prevent Disease or Abnormality	Improve Health and Vigor of Population	Reduce No. of Carriers
Australia	100[a] (100)[a]	100[a] (100)[a]	100[a] (50)	100[a] (33)	92[a] (17)	33	33
Brazil	94[a] (84)[a]	91[a] (81)[a]	88[a] (78)[a]	78[a] (41)	100[a] (66)	56 (25)	50 (6)
Canada	98[a] (98)[a]	96[a] (87)[a]	96[a] (57)	87[a] (41)	79[a] (11)	34 (11)	11 (2)
Denmark	100[a] (100)[a]	100[a] (100)[a]	100[a] (60)	85[a] (46)	100[a] (53)	57 (14)	23
FRG	98[a] (89)[a]	100[a] (89)[a]	98[a] (75)[a]	89[a] (43)	75[a] (23)	11 (4)	6
France	100[a] (94)[a]	100[a] (88)[a]	94[a] (69)	88[a] (63)	100[a] (69)	38	6 (6)
GDR	86[a] (57)	95[a] (86)[a]	76[a] (38)	71 (24)	100[a] (76)[a]	33 (5)	14 (5)
Greece	100[a] (100)[a]	83[a] (67)	100[a] (33)	83[a] (50)	100[a] (83)[a]	83[a] (33)	60 (60)
Hungary	100[a] (87)[a]	100[a] (67)	80[a] (53)	93[a] (47)	100[a] (93)[a]	87[a] (53)	53 (7)
India	100[a] (73)	96[a] (76)[a]	89[a] (42)	77[a] (35)	93[a] (78)[a]	69 (35)	69 (46)
Israel	100[a] (93)[a]	100[a] (73)	93[a] (33)	93[a] (40)	100[a] (53)	47 (13)	40
Italy	100[a] (82)[a]	100[a] (73)	91[a] (46)	64 (27)	82[a] (36)	27	18
Japan	92[a] (76)[a]	96[a] (74)	86[a] (53)	79[a] (33)	90[a] (45)	59 (20)	33 (18)
Norway	100[a] (100)[a]	100[a] (100)[a]	100[a] (67)	100[a] (50)	50 (17)	33 (33)	0
Sweden	100[a] (90)[a]	100[a] (100)[a]	100[a] (70)	75[a] (35)	90[a] (25)	30 (5)	10
Switzerland	100[a] (100)[a]	100[a] (80)[a]	100[a] (80)[a]	100[a] (20)	100[a] (40)	40 (20)	0
United Kingdom	100[a] (100)[a]	100[a] (97)[a]	100[a] (71)	87[a] (41)	97[a] (7)	23 (3)	16
United States	99[a] (97)[a]	98[a] (90)[a]	97[a] (64)	86[a] (43)	82[a] (19)	40[a] (12)	18 (2)
Overall	98[a] (92)[a]	98[a] (87)[a]	95[a] (62)	85[a] (42)	86[a] (31)	41 (14)	23 (5)
United States, 1979 (N = 205)[b]	Not Asked	98[a] (83)[a]	97[a] (75)[a]	86[a] (44)	81[a] (52)	40 (11)	19 (7)

[a] Strong consensus (≥75%) for "important" or "essential."

[b] J. R. Sorenson, personal communication.

icist with a particular background characteristic will regard a goal as important.

To see whether those who saw the most patients held different views, we also compared, for each question, the responses of the 68 (10%) who did no counseling with the responses of the 173 (26%) who counseled 10 or more patients per week.

Results

There was almost 100% consensus that three of the seven listed goals of counseling were important or essential (table 2); these three goals were (1) "helping individuals/couples understand their options and the present state of medical knowledge so they can make informed decisions" (98%), (2) "helping individuals/couples adjust to and cope with their genetic problems" (98%), and (3) "the removal or lessening of patient guilt or anxiety" (95%). In all, 86% and 85%, respectively, believed that "helping individuals/couples achieve their parenting goals" and "the prevention of disease or abnormality" were important. The majority did not consider the remaining two goals,—namely, "improvement of the general health and vigor of the population" and "a reduction of the number of carriers of genetic disorders in the population"—as important. In general, the results of the Sorenson et al. (1981) survey, listed at the bottom of table 2 for comparison, were similar. In regard to two of the seven goals, responses of geneticists who counseled 10 or more patients per week differed significantly from those who counseled none. Those who did the most counseling were more likely ($P < .001$) to consider it essential to help patients achieve their parenting goals but were less likely ($P < .04$) to consider reducing the number of carriers important.

For two goals, gender emerged as significant cross-nationally in the stepwise logistic regressions.

Table 3

Directive/Nondirective Approaches: % of 677 Respondents Believing Approach Always or Sometimes Appropriate

	APPROACH				
COUNTRY	Suggest That You Will Support Any Decisions Patient Makes	Tell Patient That Decision Is His/Hers Alone	Inform Patient What Most Others In His/Her Situation Have Done	Inform Patient What You Would Do in His/Her Situation	Advise Patient What He/She Ought to Do
Australia	100[a]	92[a]	92[a]	8[b]	8[b]
Brazil	84[a]	94[a]	59	13[b]	16[b]
Canada	94[a]	94[a]	83[a]	45	9[b]
Denmark	100[a]	100[a]	62	31	8[b]
FRG	91[a]	89[a]	48	30	9[b]
France	88[a]	73	31	38	25[b]
GDR	90[a]	86[a]	52	10[b]	0[b]
Greece	86[a]	100[a]	57	29	14[b]
Hungary	80[a]	53	53	40	40
India	77[a]	89[a]	77[a]	58	56
Israel	93[a]	100[a]	67	0[b]	20[b]
Italy	91[a]	82[a]	46	9[b]	18[b]
Japan	90[a]	81[a]	58	45	27
Norway	83[a]	83[a]	50	50	0[b]
Sweden	90[a]	100[a]	47	11[b]	10[b]
Switzerland	100[a]	75[a]	100[a]	50	0[b]
United Kingdom	100[a]	94[a]	94[a]	30	0[b]
United States	98[a]	97[a]	69	19[b]	12[b]
Overall	94[a]	92[a]	66	26	15[b]
United States, 1979 ($N = 205$)[c]	93[a]	99[a]	66	18[b]	13[b]

[a] Strong consensus (≥75%) re appropriateness.

[b] Strong consensus (≥75%) re inappropriateness.

[c] Source: Sorenson et al. 1981, p. 44.

Women were 13.2 times more likely than men to consider "helping individuals/couples understand their options" absolutely essential and were 3.5 times more likely than men to regard "removal . . . of . . . guilt or anxiety" as essential. Length of experience was also related to considering the first goal essential; for each 10 years in genetics, the odds ratio increased by 1.8. No other background variables were significant cross-nationally.

There was very strong consensus about the appropriateness of two of five approaches to counseling (table 3); Both of these—namely, (1) "suggest that while you will not make decisions for patients you will support any they make" (94%) and (2) "tell patients that decisions, especially reproductive ones, are theirs alone and refuse to make any for them" (92%)—stressed nondirectiveness. There was less consensus (66%) about the third approach—"inform patients what most other people in their situation have done"—which some geneticists regard as directive. The fourth and fifth approaches were directive: "inform patients what you would do if you were in their situation" and "advise patients what they ought to do." Relatively few geneticists (26% and 15%, respectively) considered these approaches appropriate. In general, the results of the Sorenson et al. (1981) survey, listed at the bottom of table 3, were similar.

In regard to two of the five counseling approaches, responses of those who saw 10 or more patients weekly differed from responses of those who saw none. Geneticists who saw the most patients were less likely to consider it appropriate to inform patients what they themselves would do in the patient's situation ($P < .001$) and were more likely to consider it appropriate to support patients' decisions ($P < .02$).

As with the counseling goals discussed above, we entered background variables into stepwise logistic

Table 4

Presenting Reproductive Options: % of 677 Respondents Who Would Discuss a Particular Issue, Without Giving Advice, If One Parent Carries Tuberous Sclerosis, a Dominant Disorder Not Diagnosable Prenatally

	ISSUE						
COUNTRY	Adoption[a]	AID	Taking One's[a] Chances	Contraception[a]	Sterilization[a]	Donor Egg IVF	Surrogate Motherhood
Australia	100[b]	100[b]	64 58	75[b]	91,[b] 75[b]	92[b]	46
Brazil	78[b]	50	66	63	69	59	34
Canada	98[b]	98[b]	6[b]	82[b]	89[b]	59	37
Denmark	93[b]	80[b]	53	87[b]	67, 60	80[b]	47
FRG	85[b]	72	41	68	72	33	16[c]
France	77,[b] 71	81[b]	71	53	53, 47	44	0[c]
GDR	35 55	55	30, 80[b]	25,[c] 35	30, 0[c]	25[c]	5[c]
Greece	80,[b]	67	40, 33	60, 50	50, 17[c]	80[b]	25[c]
Hungary	57, 62	47	36, 43	73, 31	77,[b] 39	46	31
India	54	54	44	50, 41	45	43	48
Israel	86[b]	100[b]	73, 69	67, 77[b]	67	80[b]	39
Italy	91[b]	80[b]	82[b]	82[b]	64, 55	64	27
Japan	25,[c] 20[c]	26	58	39, 36	19[c]	21[c]	10[c]
Norway	83,[b] 50	83[b]	67	50, 67	50	33	33
Sweden	86[b]	90[b]	68	85,[b] 90[b]	84[b]	55	30
Switzerland	80[b]	100[b]	60	60	60	80[b]	20[c]
United Kingdom	93[b]	94[b]	94[b]	90[b]	90[b]	63	27
United States	95[b]	96[b]	88[b]	85[b]	84[b]	83[b]	67
Overall	85,[b] 84[b]	83[b]	75[b]	74	74, 73	66	46

[a] Questions asked for both male and female carriers. When response re male carriers was different from that re female carriers, two numbers are given: the first number is the response re female carriers, and the second number is the response re male carriers.

[b] Strong consensus (≥75%) in favor of presenting.

[c] Strong consensus (≥75%) against presenting.

regressions. Gender was related, cross-nationally, to four of the five counseling approaches (which are listed as cols. 1 and 3–5 in table 3). Women were 2.68 times more likely than men to consider it appropriate to "suggest that while you will not make decisions . . . you will support any they make." Men were 1.9 times more likely than women to consider it appropriate to "inform patients what most other people have done," 4.6 times more likely to consider it appropriate to "inform patients what you would do if in their situation," and 6.9 times more likely to consider it appropriate to "advise patients what to do." Clearly, men favored the more directive approaches. Persons who said they were politically liberal were 3.2 times more likely than conservatives to consider it appropriate to "support any (decisions) patients make." No other background variables remained in the analyses at the .05 level.

Responses to the case vignettes regarding presenting reproductive options to carriers of tuberous sclerosis are summarized in table 4. The percentages reported comprise those who would discuss "without giving advice" and those who would discuss "the risks and potential problems involved." (Whenever responses differed according to the carrier's sex, we have listed responses for the male carrier separately.) There was strong consensus (≥75% in ≥75% of nations) about nondirective presentation of one option, adoption. Geneticists in 14 nations would discuss this; exceptions were the German Democratic Republic (GDR) and Hungary, where respondents said no babies were available, and India and Japan, where adoption is socially unacceptable to many people. AID was widely accepted; 83% would present it as an option, 3% would advise against it, 3% would advise in favor of it, and 11% would discuss it only if asked. AID is not socially accepted in Japan.

In all, 75% would present "taking their chances" of having a normal child as an option, without giving advice; 25% would advise against it. Of the total, 74% would present contraception as an option, without giving advice; 14% would advise clients to use it; and 12% would discuss it only if asked. In all, 74% and 73%, respectively, would present tubal ligation or vasectomy as options, 5% would advise in favor of sterilization, 4% would advise against it, 15% would discuss it only if asked, and 2%–3% would not discuss it at all.

IVF with a donor egg and surrogate motherhood are two new and controversial options. The first has wider acceptance, in spite of a low success rate. Of the total, 66% would present this option without giving advice, 23% would discuss it only if asked, 7% would not discuss, 3% would advise against it, and 1% would advise in favor of it. In their reasoning, respondents saw this as a less harmful option than surrogate motherhood, in spite of its technical difficulty.

There was no consensus about presenting surrogate motherhood as an option; 46% would present it without giving advice, 29% would discuss it only if asked, 18% would not discuss it at all, and 7% would advise against it. Only in the United States would a majority (67%) present surrogacy as an option unasked. Men were 4.63 times more likely than women to present surrogate motherhood as an option, 2.36 times more likely to present contraception for female carriers, and 2.25 times more likely to present IVF with a donor egg. Persons who attended 15–24 religious observances per year (regardless of religious background) were 2.0 times more likely to present taking one's chances as an option, 1.7 times more likely to present tubal ligation, 1.55 times more likely to present vasectomy, and 1.3 times more likely to present contraception for female carriers. No other background variables were significantly related at the .05 level, cross-nationally, to type of options presented.

Patient autonomy (right to decide, right to know, and making informed decisions) was the most common reason for presenting reproductive options and was cited by 67%; 14% mentioned preventing birth defects. Only 4% said that they would not discuss an option because it was the province of a nongeneticist. Fewer than 1% mentioned potential benefit or harm to society as a reason for presenting any option. In addition to giving reasons for their counseling approach, 28% discussed the specific consequences of using any of the listed options. Those who would give advice were more likely ($P < .0001$) to mention consequences than were those who would be nondirective. Ninety-two percent saw no conflict between the interests of different persons—or between individuals and society—in the use of any option, including surrogacy.

Table 5

Fetuses with Low-Burden Disorders: % of Respondents Who Would Present Full Information without Giving Advice

	DISORDER		
COUNTRY	XYY	Turner Syndrome	Possible Small NTD
Australia	92[a]	92[a]	100[a]
Brazil	84[a]	85[a]	84[a]
Canada	91[a]	98[a]	94[a]
Denmark	93[a]	100[a]	79[a]
FRG	76[a]	74	73
France	35	82[a]	56
GDR	43	52	48
Greece	86[a]	100[a]	100[a]
Hungary	33	60	47
India	77[a]	54	63
Israel	80[a]	93[a]	100[a]
Italy	82[a]	100[a]	91[a]
Japan	78[a]	77[a]	77[a]
Norway	83[a]	67	67
Sweden	90[a]	95[a]	86[a]
Switzerland	80[a]	80[a]	100[a]
United Kingdom	91[a]	97[a]	84[a]
United States	88[a]	92[a]	95[a]
Overall	84[a]	88[a]	87[a]

[a] Strong consensus (≥75%) for nondirectiveness.

There was ≥75% consensus in ≥75% of nations that counseling should be nondirective for Turner syndrome, XYY, and a possible small NTD (table 5). Eighty-four percent would be nondirective for XYY, 88% for Turner syndrome; 20% and 22%, respectively, would include a discussion of the emotional difficulties associated with terminating the pregnancy. Fourteen percent of all respondents would give optimistic information or advice about XYY, 7% about Turner syndrome; 20% considered a child with either disorder within the range of normal. In France, Hungary, and the GDR 65%, 60%, and 43%, respectively, would advise carrying an XYY fetus to term or would give optimistically slanted information. In India, 46% would advise aborting a Turner syndrome fetus or give pessimistically slanted information, citing the unmarriageability of an infertile girl and the consequent economic burden on the family. Women were 5.63 times more likely than men to be nondirective for Turner syndrome and 3.45 times more likely to be nondirective for XYY.

In the case of the possible small NTD, 98% (≥93% in each nation) would tell the couple the findings; 87% would then counsel nondirectively, 6% would advise carrying to term, and 5% would advise abortion. Exceptions to the general consensus for nondirectiveness were the GDR, Norway, Hungary, and India, where 48%, 33%, 27%, and 19%, respectively, would advise abortion, and France, where 32% would advise carrying to term. In their reasoning, 40% of the respondents cited parents' right to know, 29% cited the geneticist's obligation to tell the truth, and 17% thought that the parents had a duty to know, even if they did not want to know, and a duty to use the information in their decision making. Six percent said that the child would be in the normal range if an NTD were present. Women were 5.97 times more likely than men to be nondirective.

A comparison between the responses of those who counseled 10 or more patients weekly and the responses of those who counseled none revealed a significant difference in regard to a portion of only one of the four clinical counseling cases. Those who did the most counseling were more likely ($P < .0002$) to present adoption as an option than those who did no counseling.

Discussion

There was widespread consensus, cross-nationally, about most goals and approaches for counseling. Goals rated most important were those emphasizing the educational and psychological aspects of counseling, such as providing information as a basis for facilitating informed decisions by clients, helping clients cope, or removing clients' guilt or anxiety. The goal rated least important was the one most closely related to eugenic concerns, that is, reducing the number of carriers in the population. Preferred approaches to counseling were nondirective. Responses to four hypothetical counseling situations were also nondirective. There were some exceptions, notably the two East-European nations (the GDR and Hungary), where more directive approaches were consistently preferred. Geneticists in these nations see it as their role to give advice, direction, and guidance (Czeizel et al. 1981). In India, where counseling followed a somewhat directive course in some situations, some respondents noted that the educational and social distance between counselor and counselee is likely to be greater in India than in more developed nations; geneticists felt that they had an obligation to give direction to less educated clients.

The associations between personal background variables, especially gender, and attitudes about counseling were noteworthy. Although we had anticipated that some relationships between background and attitudes would prove to be cross-national, we expected these to be based on professional factors—such as experience, field, or degree—rather than on such personal factors as gender, political viewpoint, or religiosity, whose effects are supposedly eliminated, or at least greatly reduced, by professional training. This was not the case; most relationships were with personal—not with professional—background factors, notably gender, political preferences, and attendance at religious observances. Our findings with regard to gender contrasted with those of researchers who, in comparing views of 47 female and 59 male counselors in the United States, found no differences (Zare et al. 1984). Among our respondents, professional training has not erased background differences, at least when morally and socially problematic topics such as abortion and new reproductive options are concerned. Given the likelihood that the directiveness or nondirectiveness of counseling may be affected by the geneticist's personal background, it might be wise for clients to seek second or third opinions on a routine basis. An alternative would be for clinics to provide counseling sessions at which both male and female counselors are present.

How accurately do the survey results reflect counselors' actual practices, as opposed to counselors' attitudes and beliefs? There is no practical way to assess this without extensive field observations in the 18 nations. There are inherent but unavoidable weaknesses in the questionnaire method, no matter how carefully it is designed. No questionnaire of geneticists alone can validly assess the quality or efficacy of genetic counseling in different nations. Geneticists' widespread acceptance of the importance of many (though not all) of the listed goals of counseling may reflect their belief in the importance of their specialty rather than describe their actual counseling practices. In some nations the questionnaires may have elicited those responses that participants considered, whether consciously or unconsciously, most acceptable to their colleague who collected the questionnaires. The effects of having a senior person, usually a well-known and highly respected authority, disseminate and collect the questionnaires cannot be discounted entirely, even though responses were anonymous. The alternative, conducting the survey through unknown outsiders, would have produced a low response rate.

In genetic counseling, information exchange depends on establishing rapport with patients who may be anxious or unsophisticated, explaining unfamiliar concepts, and offering reproductive options that may deviate from accepted cultural practices (Pederson et al. 1976; Ivey 1977; Palafox and Warren 1980; Sue 1981; Yuen 1987). Nonverbal communication is an inescapable part of counseling. Even clothing and demeanor may convey the counselor's attitudes, especially to patients from a different social class or subculture. None of these nuances of communication can be covered in a questionnaire. Further, the counselor's and the patient's perceptions of what transpired in a counseling session may differ markedly (Sorenson et al. 1981; Wertz et al. 1986, and in press).

Most Western-oriented and Western-trained genetic counselors subscribe to the ideal of nondirectiveness. This highly respected goal may be unattainable in practice, but counselors should nonetheless strive to minimize their biases (Capron et al. 1979). In some nations, however, some patients may expect to be told what to do and may have little experience in making decisions. In these cases, counselors have to proceed differently, while striving to maintain the patients' dignity. This is why a worldwide consensus in counselors' attitudes is not necessarily ideal.

Nondirectiveness should not be nonsupportive neutrality. Nondirectiveness can place a heavy burden of decision making—and consequent guilt—on the patient, especially when test results are not clear (Rothman 1986). Although most geneticists agreed that they would support any decisions that patients made, we question whether this is humanly possible, given the strength with which many geneticists hold moral convictions. Saying that you will support any decisions that others make implies total moral relativism. Those engaged in counseling should consider whether this is desirable.

Medical geneticists are both physicians who serve their patients and citizens who serve as consultants to health-policy makers. In their public role as citizens they will be called to help interpret complex scientific knowledge for the benefit of society as well as of individuals. Geneticists' responses demonstrate that they are sensitive to their roles vis-à-vis individuals and families; we hope that this sensitivity also extends to their social role as citizens.

Acknowledgments

This research was supported by a grant from the Medical Trust, one of the Pew Memorial Trusts, administered by the Glenmede Trust Company, Philadelphia, and by the Muriel and Maurice Miller Foundation. Fieldwork in 1984 was supported by the Norwegian Marshall Fund. Professor James R. Sorenson, School of Public Health, University of North Carolina at Chapel Hill, permitted use of some questions from his earlier survey and of his raw data. Dr. Y. Edward Hsia, University of Hawaii at Manoa, provided valuable comments for the Discussion section.

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