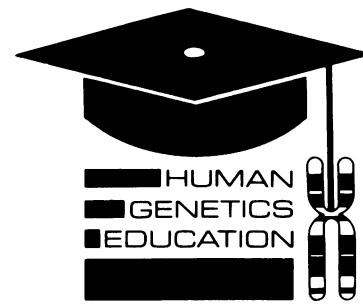


# Involvement of Rabbis in Counseling and Referral for Genetic Conditions: Results of a Survey

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## Summary

Members of the New York Board of Rabbis were surveyed in the summer of 1991 to assess their activity in counseling congregants on issues related to genetics. Of a sample of 257 members, 181 (70.4%) responded to the questionnaire, and 175 of the responses were analyzed. More than half (56.0%) of the rabbis discussed health issues as a routine part of premarital counseling, and 22.3% had counseled a couple after prenatal diagnosis of an abnormal fetus. Orthodox rabbis were more likely than rabbis from other branches of Judaism to have contacted medical personnel in these cases, and they reported more involvement in helping families after the birth of a child with a hereditary condition or birth defect. However, a majority (90.9%) of rabbis from all branches would refer such a family for genetic counseling. Ninety-four rabbis (53.7%) discussed Tay-Sachs carrier testing with congregants. These rabbis tended to be Reform, to be younger, and to have fewer years in the rabbinate. Reform rabbis also scored significantly higher than did Orthodox or Conservative rabbis on knowledge questions about Jewish genetic diseases and were more active in distributing pertinent literature to congregants. Even though nearly 90% of the sample viewed counseling on genetic issues as part of their rabbinical role, most rabbis, even those who actually counseled on these issues, felt poorly prepared to do so. Recommendations are made for increased programming in rabbinical schools and for outreach from the genetics community.

## Introduction

There is demonstrated interest among the clergy—particularly among Protestant ministers—in addressing the health problems that confront their congregants. These concerns are wide-ranging: from physical and mental illness to alcohol and drug addiction, from reproductive issues to concerns about death and dying (Brink 1977; Kaseman and Anderson 1977; Virkler 1979; Hologer 1981; Wylie 1984; Rupert and Rogers 1985; Hyman and Wylie 1990). In these studies, clergy seem to pay far less attention to genetic problems, despite the important role that religious leaders can play in the de-

livery of information, education, and support of families facing genetic diseases or birth defects (Clark 1981; Fletcher 1982). Similarly, clergy may be called on to help parents make difficult reproductive decisions, such as whether to seek prenatal testing or to continue a pregnancy after an abnormal prenatal diagnosis, decisions that may collide with the parents' ethical and religious beliefs. Support from a member of the clergy can help parents frame these decisions in a religious context and anticipate their consequences (Fletcher 1982; Baumiller 1983).

Researchers have found clergy generally unprepared to meet the needs of congregants dealing with genetic diseases, birth defects, and reproductive technologies. Mertens et al. (1986) found that a majority of clergy members whom they surveyed spent <5% of their counseling time helping parishioners to resolve dilemmas in this area. Most respondents said that they had never had any formal education to assist them in keeping up with advances in genetics and the choices now con-

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fronting their parishioners. There were no rabbis among the respondents.

Genetic and reproductive issues present special challenges for rabbis, largely because of the complexities of Jewish religious law (*halakha*) (Rosner 1979; Kukin 1981) but also because of the collective memory of Nazi attempts at genetic control during the Holocaust (Green 1985). Orthodox rabbis generally discourage prenatal testing because it may be a prelude to abortion (Brown 1990). Nevertheless, rabbis from all branches of Judaism agree that interaction with a genetic counselor is advisable when a genetic disorder or birth defect occurs in a family (Weiss 1984). While Orthodox rabbis are frequently consulted on matters such as these, Weiss found that few if any non-Orthodox rabbis function as genetic "advocates" in aiding families to understand and act on the options presented them during genetic counseling. In recent years, rabbis from all branches have been hesitant about advocating mass screening for the gene that causes Tay-Sachs disease, largely because of reservations about the stigmatization of carriers. For Orthodox rabbis, another concern was the halakhic restriction on abortion except in cases where the mother's life or health is threatened (Kenen and Schmidt 1978; Rosner 1979; Green 1985; Jenkins 1990). Many Orthodox rabbis endorsed Tay-Sachs testing only as a means to discourage the marriage of known carriers (Rosner 1989).

We designed the present study to examine the range of counseling and referral activities in genetics that were undertaken by a group of rabbis in New York City and several surrounding counties. We were also interested in how prepared these rabbis were to undertake such counseling and whether they considered it part of their rabbinical role.

## Material and Methods

In the summer of 1991, we surveyed 257 rabbis who were current members of the New York Board of Rabbis (NYBR), a unique organization embracing Orthodox, Conservative, Reform, and Reconstructionist rabbis (Ultra-Orthodox and Hasidic rabbis are not members of the NYBR). The systematic sample consisted of every other name appearing on the NYBR membership roster for New York City and several suburban counties. When possible, the names of retired rabbis and those serving in noncongregational positions were removed prior to selection of the sample.

The survey instrument consisted of 19 questions (44 items of data); most of them were forced multiple choice, but a few were open-ended questions. The

**Table 1**

### Demographic Characteristics of Respondents

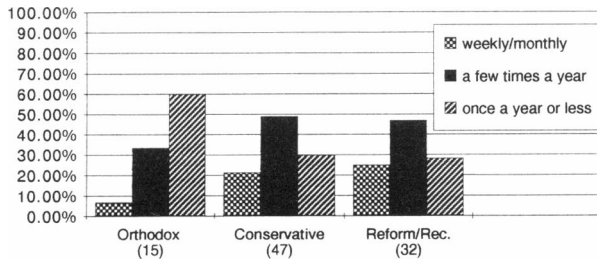
	N (%)
Sex:	
Male .....	170 (97.1)
Female .....	3 (2.9)
Age (years) (range 30–82):	
30–39 .....	25 (14.5)
40–49 .....	41 (23.7)
50–59 .....	35 (20.2)
60–69 .....	49 (28.3)
>70 .....	23 (13.3)
Branch of Judaism:	
Orthodox .....	54 (30.9)
Conservative .....	77 (44.0)
Reform .....	41 (23.4)
Reconstructionist .....	3 (1.7)
Size of congregation:	
Small (<300 families) .....	51 (35.6)
Mid-sized (300–600 families) .....	56 (39.2)
Large (>600 families) .....	36 (25.2)
	<u>Years (SD)</u>
Mean age:	
Orthodox .....	60.8 (11.7)
Conservative .....	53.8 (11.9)
Reform/Reconstructionist .....	49.5 (12.8)
Overall .....	54.9 (12.8)
Mean age at ordination:	
Orthodox .....	24.3 (2.4)
Conservative .....	27.4 (4.5)
Reform/Reconstructionist .....	28.5 (4.0)
Overall .....	26.7 (4.2)

questionnaire was pretested by members of the NYBR Board of Governors and subsequently was revised. After the initial mailing, three follow-up mailings were utilized to maximize response. Information collected from the questionnaire was analyzed with the SPSS computer analysis package by employing several statistical tests:  $\chi^2$  statistics were used to determine significant relationships between pairs of categorical variables; *t*-tests and one-way ANOVA were used to look for differences in group means on several of the variables; and logistic regression was used in an attempt to explain any interactions between variables.

## Results

### Characteristics of the Sample

One hundred eighty-one (70.4%) of the survey instruments were returned, and six were excluded from analysis because of incompleteness. Demographic characteristics of the 175 respondents are summarized in table 1. There were very few women rabbis in the sam-



**Figure 1** Frequency of self-reported counseling by rabbis about Tay-Sachs disease (N = 94).

ple; the Orthodox branch does not ordain women, and women ordained by the other branches have not yet reached significant numbers in the NYBR membership. On average, Orthodox rabbis were older and had spent more years in the rabbinate than had their colleagues in the other branches. One hundred forty-three rabbis (81.7%) were currently serving congregations, and together these rabbis served a total of 62,440 Jewish families that they reported as members of their congregations. The average rabbi served a congregation numbering 436 families. Reform and Reconstructionist rabbis served congregations nearly twice as large as those served by Orthodox rabbis.

**Prenatal Diagnosis and Contact with Genetics Personnel**

A large majority (91.4%) of rabbis reported counseling couples before marriage, and more than half (56.0%) of the sample discussed general health issues as a routine part of their premarital counseling. Thirty-nine rabbis (22.3%) had counseled a couple when prenatal diagnosis showed an abnormality in the fetus. Although rabbis of all branches reported such counseling, percentages were higher for Reform rabbis (33.0%) than for Orthodox (22.2%) or Conservative rabbis (20.8%). Although 41% of the 39 rabbis said that they had been in direct contact with the medical personnel treating the couple, Orthodox rabbis were more than twice as likely to have had such contact. Similarly, more Orthodox rabbis (44.4%) reported helping families

after the birth of a child with a hereditary condition or birth defect than did either Reform (38.6%) or Conservative rabbis (37.7%). It is interesting that rabbis doing this type of counseling were significantly older ( $t = 2.04$ ;  $df = 171$ ;  $P = .043$ ) and more experienced ( $t = 2.27$ ;  $df = 163$ ;  $P = .024$ ). A test of logistic regression failed to find a significant effect for either of these variables over affiliation.

When asked whether they would refer a family whose child was born with a genetic problem or birth defect for genetic counseling, 159 (90.9%) said that they would. Thirteen rabbis either indicated that they were unsure about how to answer this question or left it blank. Of the three rabbis who would not refer congregants to genetic services, only one stated that he felt that this practice might lead to the performance of an abortion.

**Counseling about Tay-Sachs Disease**

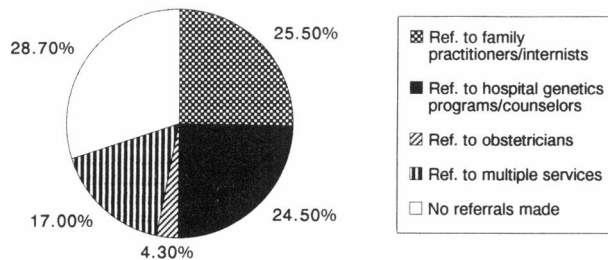
Ninety-four rabbis (53.7%) reported discussing Tay-Sachs carrier testing with congregants, three quarters of them only a few times a year or less. Orthodox rabbis were significantly less likely than their colleagues in other branches to discuss the issue of Tay-Sachs carrier testing with congregants ( $\chi^2 = 22.67$ ;  $P = .00001$ ) (fig. 1). Rabbis who were active in this area also tended to be younger, to have fewer years of experience in the rabbinate, and to serve larger congregations. Table 2 shows the differences in means for the two groups on these variables. Again, a test of logistic regression failed to find significant effects for any of these variables over and above affiliation, or vice versa.

Most (70.2%) of the rabbis initiated the subject of carrier testing themselves, but 27.7% said that their congregants had broached the matter first. After discussing carrier testing, 67 (71.3%) of the 94 rabbis made further referrals. However, only a third of these referrals were to genetic service programs (fig. 2). More than a quarter (27) of the 94 rabbis made no referrals at all. Referral rates for carrier testing did not differ significantly by affiliation. Of the 15 rabbis expressing reserva-

**Table 2**

**Comparison of Tay-Sachs Counseling Activity, by Age, Years in Rabbinate, and Size of Congregation**

	Active (SE)	Not Active (SE)	t	df	P
Age (years) . . . . .	52.4 (1.2)	57.9 (1.5)	-2.87	171	.005
Years in rabbinate . . . . .	25.3 (1.4)	31.5 (1.7)	-2.88	169	.005
No. of families . . . . .	495.1 (32.3)	351.8 (33.4)	3.01	141	.003



**Figure 2** Referral patterns of rabbis who counsel for Tay-Sachs carrier testing (N = 94).

tions about discussing Tay-Sachs testing with congregants, most, but not all, were Orthodox.

### Knowledge about Jewish Genetic Diseases

Questioning rabbis about the carrier rate in the Jewish population was one way to assess their knowledge about Tay-Sachs disease. In response to a forced-choice question, only 42 rabbis (24.0%) knew that 1 in 25 Ashkenazi Jews carries the recessive gene for Tay-Sachs disease. Over half the rabbis thought that the correct number was somewhere between 1 in 100 and 1 in 250; 29 rabbis (16.6%) said that they did not know the correct answer, and 13 (7.4%) said that it was 1 in 10.

Recoding the rabbis' answers as "Incorrect" (1) and "Correct" (2) yielded the information shown in table 3. This table shows that, of the 145 rabbis who answered the question, Reform and Conservative rabbis answered correctly significantly more often than did Orthodox rabbis. Similarly, only 9.3% of Orthodox rabbis were able to name a Jewish genetic disease other than Tay-Sachs disease, as compared with 22.1% of Conservative rabbis and 22.7% of Reform rabbis. It is important to note, however, that both age and number of years in the rabbinate contributed to these results: rabbis answering incorrectly on the knowledge question were an average of 7 years older ( $t = 3.28$ ;  $df = 141$ ;  $P = .001$ ) and had been ordained for more years ( $t = 3.33$ ;  $df = 140$ ;  $P = .001$ ). However, tests of logistic regression found no significant effects for age or experience over affiliation, and vice versa, on this question.

**Table 3**

**Knowledge of Tay-Sachs Carrier Rate, by Branch**

	Orthodox	Conservative	Reform	Overall
Incorrect answer . . . . .	90.0%	64.7%	62.2%	71.0%
Correct answer . . . . .	10.0%	35.3%	37.8%	29.0%
N . . . . .	40	68	37	145 (100.0%)

NOTE.— $\chi^2 = 9.731$ ;  $df = 2$ ;  $P = .008$ .

When asked about their educational preparation in Jewish genetic diseases, 89.1% of the total sample said that they had never taken a course or attended a workshop or lecture dealing with this topic. Of the 19 rabbis who had attended such a course, only 2 said that they had taken it in rabbinical school; the others had been exposed to the material at rabbinical meetings or workshops or lectures held at medical facilities.

Despite a lack of knowledge about Jewish genetic diseases, the overwhelming majority of rabbis expressed a willingness to learn about and disseminate this information to congregants. Although 75 rabbis (42.9%) had distributed pamphlets about Tay-Sachs disease and carrier testing to congregants, 95.8% of those who had never distributed this literature said that they would do so if it were made available to them. Some rabbis showed surprise that such literature even existed.

While neither age, experience, nor size of congregation was a factor in whether rabbis had taken special courses or workshops on Jewish genetic diseases, affiliation was strongly related to the practice of distributing educational material about these conditions to congregants. Conservative rabbis reported giving out this literature more than twice as often as did Orthodox rabbis, and Reform rabbis did so more than three times as often ( $\chi^2 = 19.706$ ;  $P = .00005$ ). Virtually equal proportions of rabbis from all branches indicated a willingness to distribute educational materials about Tay-Sachs disease if it were made available to them.

### Perceptions of Preparedness and the Counseling Role

The rabbis were asked how well their rabbinical training had prepared them to counsel congregants about Jewish genetic diseases. Four response categories were used, ranging from "very well prepared" to "very poorly prepared." Although the great majority of rabbis reported low levels of preparedness, Reform rabbis felt less poorly prepared, in addressing these issues, than did their Orthodox or Conservative colleagues. When the rabbis were divided into two groups—those who felt well prepared to counsel in this area and those who

**Table 4**

**Relationship of Age, Years in Rabbinate, and Size of Congregation to Acceptance of Counseling Role in Jewish Genetic Diseases**

	Acceptance (SE)	Nonacceptance (SE)	<i>t</i>	df	<i>P</i>
Age (years) .....	53.9 (.9)	65.4 (3.1)	-3.54	169	.001
Years in rabbinate .....	27.0 (1.1)	41.0 (3.2)	-3.76	167	.000
No. of families .....	440.2 (24.5)	244.3 (55.4)	1.81	140	.073

felt poorly prepared to do so—Orthodox rabbis reported significantly lower levels of preparedness than did their colleagues ( $F = 3.71$ ;  $P = .027$ ). Age, years of experience, and size of congregation were not contributory, and the group of rabbis who actually counseled congregants about Tay-Sachs disease did not feel significantly better prepared than did the group of rabbis who were not engaged in counseling.

These findings contrasted markedly with the rabbis' perceptions about what they *ought* to be doing about these issues. Asked whether they viewed counseling about Jewish genetic diseases as part of their rabbinical role, 157 (89.7%) said that they did. Willingness to undertake such a counseling role was characteristic of all branches. Over 90% of rabbis also recommended that programs on Jewish genetic diseases be offered as part of rabbinical training.

Although Reform and Conservative rabbis showed significantly more acceptance of a counseling role in this area than did Orthodox rabbis ( $\chi^2 = 8.441$ ;  $P = .015$ ), significant differences appeared again for the variables of age and years in the rabbinate. Table 4 summarizes these findings. It is not surprising that rabbis already active in counseling about Tay-Sachs disease showed a high degree of acceptance of a counseling role in this area ( $\chi^2 = 12.436$ ;  $P = .0004$ ).

When asked to list the health-related topics that they thought should be covered during rabbinical training, rabbis cited topics in genetics less often than they cited other health issues, although a sizable number did want to learn more about Jewish genetic diseases. Many reported needing help with their counseling skills and wanted to learn more about specific resources where they could refer congregants for genetic counseling and testing.

## Discussion

Rabbis in this sample were moderately active in discussing matters relating to genetics, including abnormal prenatal diagnosis, with congregants. Even Orthodox rabbis, most of whom would be opposed to abortion

unless the mother's life were endangered, were approached by congregants under these circumstances. This finding is encouraging, given the often-expressed desire of parents to have a member of the clergy involved in the difficult and emotionally charged situation of a prenatal diagnosis of abnormality (Clark 1981; Baumiller 1983; Babb et al. 1990). The finding that Orthodox rabbis interacted with physicians and genetic counselors treating such couples far more often than did their Reform or Conservative colleagues supports the conclusions of Weiss (1984), who found that few non-Orthodox rabbis were active in these situations. It remains to be explored whether, under these circumstances, Orthodox rabbis function more as advisors on the applicability of *halakha* to decision-making than as supportive counselors. After the birth of an affected child, few rabbis in the sample—whether Orthodox, Conservative, or Reform—had any hesitations about recommending a family for genetic counseling.

As a group, the sample of rabbis reported only modest activity in recommending carrier testing for the gene causing Tay-Sachs disease. A possible explanation for this is the underestimation by rabbis, in all branches, of the carrier rate in the Ashkenazi Jewish population. This underestimation may be a direct result of the very low number of babies with Tay-Sachs disease who are born each year (Sandhoff et al. 1989).

Of the rabbis who referred congregants for testing, most steered them to family practitioners and internists. Physicians as a group have a poor track record of referring their own patients for Tay-Sachs carrier testing (Beck et al. 1974; Lowden 1978; Shapiro and Shapiro 1989). Only four rabbis (4.3%) made referrals to obstetricians, who have a far better record of suggesting Tay-Sachs carrier testing (Shapiro and Shapiro 1989). Only about a quarter of the referring rabbis sent congregants directly to hospital genetics programs or testing centers.

## Variables Associated with Counseling Behavior

The factors of age and years of experience were strongly associated with levels of counseling activity in



the area of genetics. Younger, less experienced rabbis counseled more frequently, were more knowledgeable about Tay-Sachs disease, and were more likely to see such counseling as part of their rabbinical role. The only area in which older, more experienced rabbis were significantly more active was in helping a family after the birth of a child with a genetic condition or birth defect. However, because Orthodox rabbis in the sample were an average of 7 years older than Conservative rabbis and 11 years older than Reform rabbis, rabbinical affiliation partially accounts for the effects of age.

The other variable of consistent interest was rabbinical affiliation. Reform rabbis counseled more often about carrier testing for Tay-Sachs disease than did their colleagues, were more likely to distribute information on Tay-Sachs disease to congregants, and, together with Conservative rabbis, felt more comfortable about accepting a counseling role in these matters. Orthodox rabbis talked to congregants significantly less often about Tay-Sachs carrier testing. This is in sharp contrast to their greater involvement when there is a pre- or postnatal abnormality, as demonstrated by this study. It is interesting that ultra-Orthodox and Hasidic rabbis in New York, unfortunately not represented in this sample, have displayed an intense interest in the primary prevention of Tay-Sachs disease through computerized testing programs that avoid matchmaking between known carriers (Lefkowitz 1992). Orthodox rabbis in the sample appear to know less about Jewish genetic diseases than do their colleagues, perhaps because they serve smaller congregations and have fewer opportunities to interact with congregants on these issues, especially if families are older and past childbearing years. In any case, it does not appear that Orthodox rabbis fail to counsel on Tay-Sachs disease because they *object* to carrier testing. Only 10 (18.5%) of the 54 Orthodox rabbis in the sample expressed any reservations about carrier testing. It is likely that poor preparedness is an important factor explaining low levels of counseling activity.

Throughout this study, the variables of age, years of experience, and rabbinical affiliation were so highly correlated that it was impossible to disentangle their effects over and above one another. For example, although younger age, fewer years of experience, and Reform affiliation were good predictors of knowledge about Tay-Sachs disease, counseling activity, and role acceptance, this study could not determine which of these variables contributed significantly, over and above the other two, to these results. The same can be said for the effects of older age, more experience, and Orthodox affiliation on the tendency of rabbis to inter-

act with congregants after the birth of a child with an abnormality.

#### *Preparation to Counsel on Health Issues*

Despite their overwhelming (89.7%) acceptance of a counseling role on genetic issues, most rabbis in the sample feel poorly prepared to undertake it. This sense of unpreparedness is common to rabbis of all branches, ages, and years of experience and to rabbis who already help congregants with these problems, as well as to those who do not. In the case of Jewish genetic diseases, a very low level of perceived preparedness, combined with very high approval of a counseling role for rabbis, suggests the need for educational intervention in this area. In fact, large majorities from each of the branches recommended programs and courses to teach rabbis about Jewish genetic diseases in rabbinical school, as well as to help them strengthen their counseling skills and build referral networks. Although another phase of this study (authors' unpublished data) found health-related material already included in the seminary curricula of each of the four major branches, genetics and Jewish genetic diseases receive little attention. This omission may be shortsighted. DNA-based carrier tests for cystic fibrosis will soon be widely available and are likely to generate, for Jewish families, more dilemmas about who should be tested and what should be done about abnormal test results (Beaudet 1992). In addition, genetic therapies available in the near future will offer an array of choices for treating individuals with hereditary diseases and birth defects, some of them even before birth. These developments are likely to pose new ethical questions for Jewish parents, which will certainly be shared with their rabbis.

It is unlikely that courses or special programs on genetic issues were available to rabbis in the present sample, who were ordained an average of 28 years ago. In fact, most rabbis said that, even up to the time of this survey, they had never taken a course or attended a workshop on Jewish genetic diseases. Although this was a cross-sectional study, the strong differences on the variables of age and experience suggest that the role expectations of rabbis may have expanded in the years since most members of the sample were ordained. The advances in genetics that we have witnessed over the past few decades may well have raised expectations in members of the Jewish community that their rabbis will help them to face these challenges, as well as those to come, within the context of shared Jewish values and beliefs.

In light of both the difficulty in assuring access to genetic services and increasing public knowledge about



genetics, the challenge to the genetics community is clear. In this survey, rabbis from all branches of Judaism have indicated both their willingness to involve themselves in the genetic concerns of their congregants and their current lack of preparedness to do so. Student rabbis and their teachers would welcome courses taught by genetics professionals in the seminaries. Such courses could be designed to inform them of developments in genetic testing and new therapies, as well as to improve their counseling and referral skills. Congregational rabbis would be likely to attend programs and workshops for clergy that are offered by medical or university facilities, national genetics organizations, or voluntary agencies such as the March of Dimes—Birth Defects Foundation, National Tay-Sachs and Allied Diseases Association, National Gaucher Foundation, Cystic Fibrosis Foundation, and others. Rabbis should be viewed as allies in the effort to educate the public about the choices in genetics that are likely to confront all of us in the decades to come.

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