Attitudes Toward Genetic Testing in Patients At Risk for HNPCC/FAP and the German Population

HENDRIK BERTH, FRIEDRICH BALCK, and ANDREAS DINKEL

ABSTRACT

Adequate knowledge regarding hereditary diseases and genetics, as well as personal attitudes toward gene tests, are major determinants of optimal utilization of genetic testing. In the present study, we aimed to explore the general attitudes toward genetic testing in a sample representative of the German general population ($n = 2,076$) and to compare the attitudes of persons at risk for hereditary non-polyposis colorectal cancer/familial adenomatous polyposis (HNPCC/FAP) ($n = 36$) who had attended a university genetic counseling service, with a matched general population sample. We administered a subset of a questionnaire previously used in a Finnish study (Jallinoja et al., 1998). The 12 statements pertain to approval, disapproval, and concern for genetic testing. Overall, the results reveal high approval of genetic testing in the German population and in at-risk persons. In accordance with other studies, we find that the attitudes of individuals for whom hereditary disease is a salient issue of personal relevance and the attitudes of the general public are very similar. Only a few significant differences between these two samples emerged, indicating that at-risk persons hold a more favourable view of the testing. One intriguing finding was the high rate of “don’t know” responses, especially in the general population sample. Compared to results from Finland, approval of genetic testing is lower in the German population, and endorsement of “don’t knows” is remarkably higher. We argue for increased attention to the issue of attitude change after genetic counseling and for the need of comparative cross-cultural research on attitudes toward gene technology.

INTRODUCTION

Genetic susceptibility testing for hereditary cancer diseases is developing rapidly. Although a recent twin study in cancer (Lichtenstein et al., 2000) has raised the question of overemphasizing the impact of inheritance, it is clear that specific genes do contribute significantly to a heightened risk for many tumor types (see Risch, 2001, for an appraisal of this topic). Because of the increasing availability of reliable and low-cost gene tests, presymptomatic genetic testing is being facilitated for more and more diseases. This has led researchers in the fields of both medical and social sciences to discuss the potential of population-based screenings and the possibility of integrating genetic technologies and research results in public health programs (Coughlin and Miller, 1999; Khoury et al., 2000; Beskow et al., 2001).

As Hietala et al. (1995) point out, the optimal utilization of genetic testing is dependent on adequate knowledge of the benefits and risks of gene tests and molecular medicine, as well as the attitudes of the potential consumers. Yet, studies have shown that there often is a lack of understanding about personal risk for hereditary diseases and genetics in the lay public (Richards, 1996; Henderson and Maguire, 1998, 2000), which may be partly responsible for unrealistic expectations of the potential of molecular medicine in persons interested in genetic testing (Press et al., 2001). It can be assumed that lay misconceptions are in part due to the media conveying an ultimately positive view of the possibilities of gene technology (Singer et al., 1999; Petersen, 2001).

Consequently, continuing education of the public about the true possibilities and limits, as well as potential harms, of genetic testing is regarded as necessary (see Barns et al., 2000; Terry and Davidson, 2000; Fraser, 2001). However, it is likely that the vast quantity of information about new achievements and promises of gene technology reported by the mass media leaves the general public in a state of confusion, resulting in
misconceptions. This may coincide with fears that some people may hold concerning the general advancement of modern (bio)technology, creating multiple and diverse influences on attitudes toward the development and application of gene-technology in general, and genetic testing in particular.

The issue of people’s attitudes toward genetic testing is important because of the efforts expended in establishing services that are accepted by the public and in concordance with people’s needs (see Michie et al., 1995). Many studies have investigated individuals attitudes toward genetic testing and their association with the interest in undergoing genetic testing (e.g., Bluman et al., 1999; Hamann et al., 2000). Some authors have conceptualized attitudes as perceived benefits and perceived barriers or costs of genetic testing, and have used the Health Belief Model (Rosenstock, 1974) to explain utilization of genetic testing. For example, Cappelli et al. (1999) have shown that attitudes (in the sense of benefits and costs) were not only predictive of interest in genetic testing, but also predictive of actual contact with a genetic counselor. It is reasonable to conclude that attitudes—like other psychological and psychosocial factors, for instance psychological distress (Lerman et al., 1997), dispositional optimism, and family structure (Biesecker et al., 2000)—are relevant determinants of interest in, and the decision to undergo, genetic testing.

The personal attitudes of individuals interested in genetic testing are embedded in society’s discourse of gene technology and influenced by normative preferences. Therefore, knowledge regarding the general public’s attitudes toward genetic testing is highly desirable. Most studies involving the general public have focused on interest in genetic testing and attitudes toward gene tests for specific diseases, with some exceptions (O’Connor and Cappelli, 1999; Neumann et al., 2001) mostly cancer (Smith and Croyle, 1995; Andrykowski et al., 1996; Tambor et al., 1997; Ulrich et al., 1998; Bosompra et al., 2000, 2001). To date, only a few studies have investigated general attitudes toward genetic testing in population-based samples.

For example, in a nationally representative U.S. American sample, Singer et al. (1999) found that the percentage of respondents who stated that gene tests will do more good than harm rose from 47.3% in 1990 to 49.2% in 1996, although this change was not statistically significant. Shaw and Bassi (2001) conducted a general population survey and asked subjects to indicate their agreement with 11 statements concerning potential benefits and problems with genetic testing for inherited diseases. A factor analysis of the data yielded three distinct factors, which could be characterized as “genetic testing is beneficial,” “genetic testing is wrong,” and “genetic testing is dangerous.” The results revealed that respondents generally held a favorable attitude toward gene tests, which was predictive of a higher interest in engaging in genetic testing, but that they also were aware of possible disadvantages. Respondents were especially concerned about negative effects of genetic testing if it would be conducted “by the wrong people.” In fact, the results make clear that people can have positive and negative views of genetic testing at the same time, emphasizing that it is overly simplistic to reduce public’s opinion to a general pro or con.

These results of Shaw and Bassi (2001) are completely in line with research by Jallinoja et al. (1998), who analyzed the pattern of contradictory attitudes in the general population. They showed that people tend to hold a favorable view of genetic testing in general, while simultaneously disapproving specific aspects. The data of this latter report were drawn from one of the largest studies about attitudes toward genetic testing in the general population, to date. In this survey, more than 1,000 persons representative of the Finnish population were participants. Aro et al. (1997) report that there were significant age, education, and gender differences, e.g., young people were more favorable toward genetic testing, and persons with higher education levels held a more critical view concerning gene tests. The results revealed that, overall, there was a high rate of acceptance of genetic testing in the Finnish population; more than 90% agreed that genetic testing should be available to anyone who wants to know whether he or she carries disease genes. A slightly lower rate of agreement to that statement (86%) was found in a second representative survey in the Finnish community that was conducted 3 years later, and that revealed an association between level of knowledge about genes and attitudes about gene tests (Jallinoja and Aro, 2000).

In comparing the attitudes of the general Finnish population with the attitudes held by family members of patients with aspartylglucosaminuria (AGU), Hietala et al. (1995) report concordance between attitudes held by the general public and family members of patients with this hereditary disease, with family members showing a higher approval of genetic testing in some particular aspects. Similar results were obtained by Cappelli et al. (2001), who compared women from the general population and a high-risk group of women who had at least one first-degree blood relative diagnosed with breast cancer, on their attitudes toward genetic testing (perceived benefits and perceived costs). Results showed that there were only minor differences between the two groups on the attitudes measure.

In Germany, as in many other countries, there is an ongoing debate about the further advancement of gene technology and gene tests. Yet, research concerning psychosocial aspects of genetic testing and its impact on individuals and their families is still in its infancy (Fallier, 1997; Hoffnerbert et al., 2000; Keller, 2000; Balck and Berth, 2002). Particularly, knowledge regarding attitudes toward genetic testing is sparse and limited to special populations (see, e.g., Kreuz, 1996; Jacobs et al., 2001). Hence, we have aimed to explore the general attitudes toward genetic testing in the German population.

Analogous to the study design of Hietala et al. (1995), we have further attempted to compare attitudes between the general population and a sample of individuals for whom genetic disease is a salient issue of personal relevance; in our case, persons at risk for nonpolyposis colorectal cancer (HNPCC) and familial adenomatous polyposis (FAP). HNPCC accounts for about 3–5%, and FAP for about 1%, of all colorectal cancers. In Germany, the annual incidence of colorectal cancer is about 50,000 persons (Bundesärztekammer, 1998).

Identification of asymptomatic individuals who are gene carriers seems to be very desirable in these cases. As recent studies have shown, regular surveillance for early signs of disease and screening increases survival rates in both HNPCC and FAP (Heiskanen et al., 2000; Järvinen et al., 2000). Therefore, undergoing genetic testing is likely to improve the quality of life of those persons identified as HNPCC or FAP mutation carriers (see also American Gastroenterological Association, 2001).
**METHODS**

In the spring of 2001, we conducted a survey in a sample of \( n = 2,076 \) persons representative of the general population in Germany, and in a sample of \( n = 36 \) persons with a high risk for HNPCC or FAP who had an interest in knowing their carrier status and had attended genetic counseling at the Department of Clinical Genetics at the Universitätsklinikum Carl Gustav Carus in Dresden.

The general population sample was a stratified sample and met age, gender, educational level, and rural/urban place of residence quotas. These data were gathered by trained interviewers of a marketing research company (USUMA, Berlin) as part of a larger multiple-issues survey. Subjects were personally approached in their homes and they filled in the questionnaire while the interviewer was present.

Forty-nine individuals who were interested in knowing their carrier status and had attended genetic counseling received the questionnaire by mail and were asked to return it in a prepaid envelope. Thirty-six (73.5%) of these subjects participated in the current study. Of these, \( n = 30 \) (83.3%) were at-risk persons for HNPCC, and \( n = 6 \) (16.7%) were persons at risk for FAP. Twenty-five (69.4%) persons were healthy first-degree relatives of patients, and 11 (30.6%) were suffering from colon cancer. For statistical comparison, a matched sample (\( n = 36 \)) was drawn from the representative sample by selecting a control case for each respondent from the group of at-risk persons. The matching criteria were gender, age, partnership, and level of education (see Table 1 for sociodemographic characteristics of the study samples).

Subjects were administered a self-reporting questionnaire originally used in a study in Finland (Hietala et al., 1995; Aro et al., 1997). We only used a subset of the items from the complete questionnaire set (see Jallinoja et al., 1998). Thus, the questionnaire consisted of 12 Likert-like statements relating to approval, disapproval, and concern for genetic testing (see Table 2).

The first nine statements were rated on a 5-point-scale (agree, partly agree, partly disagree, disagree, don’t know). For current purposes, the item responses were combined to agree (agree and partly agree), disagree (partly disagree and disagree), and don’t know. Four of the statements pertain to approval and five to disapproval of gene tests. The last three items were rated on a 4-point-scale (not at all, somewhat, much, don’t know), they relate to reasons for concern for genetic testing.

We tabulated the responses and conducted chi-square analysis to compare the distribution of responses between the matched sample and the sample of risk persons. Because the sample size was small, we allowed effects that were significant at the 0.10 level to be interpreted as meaningful.

**RESULTS**

Although it is beyond the scope of the current paper, we first briefly want to point out that there is a striking difference between the general population sample as a whole and the matched sample, concerning the approval of gene tests. The largest difference relates to statement four, with a difference of 19% between both samples. There are also differences between the samples in disapproval of gene tests and in concern for genetic testing, but these are less pronounced. We will consider this phenomenon in the Discussion section.

Comparing the matched sample and the sample of at-risk persons, only a few statistically significant differences emerge. Overall, the results reveal that both the general population and the at-risk persons hold a favorable attitude toward genetic testing (see Table 3).

While all of the at-risk persons (100%) agreed that genetic testing should be available to anybody who wants to know about his/her disease, about 72% of the matched sample expressed their agreement with that statement (\( p < 0.01 \)). Further, more of the at-risk persons agreed that genetic testing is acceptable, because people have the right to know (\( p < 0.05 \)). For the remaining two statements concerning approval of genetic testing, there was a higher rate of agreement in the sample of at-risk persons, but these differences did not reach statistical significance.

In accordance with a more favorable view of genetic testing, *i.e.*, a high agreement with approval statements, the agreement

| Table 1. Sociodemographic Characteristics of Study Samples |
|---------------|---------------|---------------|
|               | Representative sample (\( n = 2,076 \)) | Matched sample (\( n = 36 \)) | At-risk persons (\( n = 36 \)) |
| Age (in years) | Mean 48.08 | 42.22 | 42.22 |
|               | SD 17.68 | 16.45 | 16.45 |
|               | Range 14–95 | 18–74 | 18–74 |
| Sex | Male 978 (47.2%) | 15 (41.7%) | 15 (41.7%) |
|     | Female 1,098 (52.8%) | 21 (58.3%) | 21 (58.3%) |
| Partnership (married/living together) | Yes 1,225 (59.0%) | 21 (58.3%) | 20 (55.6%) |
|     | No 851 (41.0%) | 15 (41.7%) | 16 (44.4%) |
| Education | Lower 1,716 (82.7%) | 27 (75.0%) | 25 (77.8%) |
|     | Higher (college) 360 (17.3%) | 9 (25.0%) | 11 (22.2%) |

*Note: Percentages may not sum to 100 due to rounding error or questions not answered.*
with the statements concerning negative aspects of gene tests (items 5–9) was lower in the sample of at-risk persons compared to the matched general population sample. Statistically significant differences were again observed for two items. Only about 5% of the at-risk persons stated that there are more important public health problems, compared to a quarter of the matched sample who agreed that genetic testing is not acceptable because other health care issues should be addressed first (p < 0.05). Furthermore, a higher percentage of the matched sample thought that genetic testing may lead to discrimination against disease gene carriers, but this difference was only statistically significant at the 10% level.

Regarding concerns about genetic testing (questions 10–12), at-risk persons were slightly more worried about the confidential use of test results ("... used for scientific purposes ...", "... could get into outsider's hands.") than the matched sample. However, these differences were again only significant at p < 0.1 (Table 4).

Finally, it is noteworthy that the response category "don't know" was chosen to a lesser degree by the at-risk persons in eight out of the twelve statements.

**DISCUSSION**

Our study has attempted to explore differences and similarities in general attitudes toward genetic testing between patients at risk for HNPCC/FAP and the general population in Germany. Before further discussion, a note on the different approval rates of the general population and the matched general population sample seems necessary. As mentioned above, our matching criteria were gender, age, partnership (married or living together), and level of education. We did not match for religious affiliation because this was not available for the sample of at-risk persons. However, membership in a religious group emerged as a most important factor regarding differences in attitudes toward genetic testing in the German population (see Berth et al., 2002b), with religious people being the least in fa-

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**Table 2. Attitudes Questionnaire**

<table>
<thead>
<tr>
<th>Reasons for and against acceptance of genetic testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Genetic testing should be available to anybody who wishes to have information about her/his diseases.</td>
</tr>
<tr>
<td>2) Genetic testing is acceptable because it would save the government money by reducing the cost of health care.</td>
</tr>
<tr>
<td>3) Genetic testing is acceptable because people have the right to know about their genes so that they can influence their own health and life.</td>
</tr>
<tr>
<td>4) Genetic testing is acceptable because new technologies has made it possible to detect the underlying causes of genetic diseases.</td>
</tr>
<tr>
<td>5) Genetic testing should not be performed to all.</td>
</tr>
<tr>
<td>6) Genetic testing is not acceptable because there are more important public health problems that need to be addressed first.</td>
</tr>
<tr>
<td>7) Genetic testing is not acceptable because the natural order should be respected.</td>
</tr>
<tr>
<td>8) Genetic testing is not acceptable because the results may lead to discrimination against disease gene carriers.</td>
</tr>
<tr>
<td>9) Genetic testing is not acceptable because testing would make abortions more common.</td>
</tr>
</tbody>
</table>

**Table 3. Reasons For and Against Acceptance of Genetic Testing (Percentages)**

<table>
<thead>
<tr>
<th>Question</th>
<th>Representative sample (n = 2,076)</th>
<th>Matched sample (n = 36)</th>
<th>At-risk persons (n = 36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)***</td>
<td>Agree: 58.8, Disagree: 26.5, Don’t know: 13.0</td>
<td>Agree: 72.2, Disagree: 16.7, Don’t know: 11.1</td>
<td>Agree: 100.0, Disagree: 0.0, Don’t know: 0.0</td>
</tr>
<tr>
<td>2)</td>
<td>Agree: 55.2, Disagree: 27.4, Don’t know: 15.8</td>
<td>Agree: 72.2, Disagree: 13.9, Don’t know: 13.9</td>
<td>Agree: 80.6, Disagree: 11.1, Don’t know: 5.6</td>
</tr>
<tr>
<td>3)**</td>
<td>Agree: 57.5, Disagree: 27.7, Don’t know: 13.0</td>
<td>Agree: 72.2, Disagree: 19.4, Don’t know: 8.3</td>
<td>Agree: 94.4, Disagree: 0.0, Don’t know: 5.6</td>
</tr>
<tr>
<td>4)</td>
<td>Agree: 64.3, Disagree: 21.1, Don’t know: 12.7</td>
<td>Agree: 83.3, Disagree: 8.3, Don’t know: 8.3</td>
<td>Agree: 94.4, Disagree: 2.8, Don’t know: 2.8</td>
</tr>
<tr>
<td>6)**</td>
<td>Agree: 31.2, Disagree: 47.3, Don’t know: 19.1</td>
<td>Agree: 25.0, Disagree: 58.3, Don’t know: 16.7</td>
<td>Agree: 5.6, Disagree: 86.1, Don’t know: 8.3</td>
</tr>
<tr>
<td>7)</td>
<td>Agree: 31.9, Disagree: 49.3, Don’t know: 16.9</td>
<td>Agree: 25.0, Disagree: 63.9, Don’t know: 11.1</td>
<td>Agree: 11.1, Disagree: 83.3, Don’t know: 5.6</td>
</tr>
<tr>
<td>8)*</td>
<td>Agree: 37.6, Disagree: 41.0, Don’t know: 19.7</td>
<td>Agree: 41.7, Disagree: 47.2, Don’t know: 11.1</td>
<td>Agree: 13.9, Disagree: 61.1, Don’t know: 16.7</td>
</tr>
<tr>
<td>9)</td>
<td>Agree: 31.9, Disagree: 45.6, Don’t know: 20.7</td>
<td>Agree: 30.6, Disagree: 52.8, Don’t know: 16.7</td>
<td>Agree: 11.1, Disagree: 63.9, Don’t know: 25.0</td>
</tr>
</tbody>
</table>

Note: Percentages may not sum to 100 due to rounding error or not answered questions.

***p < 0.01, **p < 0.05, *p < 0.1 χ² test, df = 2 matched sample vs. risk persons.
vor of genetic testing. Whereas 62.8% of the general population (corrected for the matched sample) indicated religious membership, only 38.9% of the matched general population sample did so. This different rate of religious identification of the two samples probably accounts for the different approval rates. The resulting matched sample represented the best fit regarding matching criteria, but, as indicated, we cannot rule out the possibility that the results are influenced by an important underlying factor which we could not control.

Regarding our main question, the results reveal that there is high rate of approval of gene tests, in both samples. In accordance with other studies (Hietala et al., 1995; Cappelli et al., 2001), we found that attitudes toward genetic testing by the general public and by persons for whom genetic disease is of personal relevance are very similar. However, it is also important to note that there was some divergence of opinion in some specific aspects. In sum, these differences indicate an even more favorable view of genetic testing in the sample of at-risk persons.

Interestingly, at the same time there was a trend toward greater concern about the confidential use of test results in persons at risk for colorectal cancer. It also appears that attending genetic counseling sessions has raised awareness regarding the potentially beneficial personal effects of the availability of genetic testing. This is indicated by a 100% agreement with the statement that anybody who wants to know about his/her disease should have the possibility of undergoing genetic testing. Perhaps the high approval rates in our sample of at-risk persons reflect satisfaction with the genetic counseling process. On the other hand, the experience of attending a genetic counseling center at a university clinic and disclosing relevant personal and family data might simultaneously have increased worries and uncertainties about the further scientific use of these data, despite having consented to provide this information for research purposes.

The pattern of high rates of approval and satisfaction, as well as high rates of coexisting concern is also reported in the literature on genetic testing for HNPCC. For example, Esplen et al. (2001) who reported on individuals who had undergone genetic testing, found that 92% of the persons were highly satisfied with the decision to participate. Nevertheless, 59% of the respondents, stated that test results would have a significant impact on their life, and 33% expressed concern about discrimination in medical and life insurance.

Disapproval of genetic testing because of fears regarding discrimination of disease gene carriers was less pronounced in our sample of at-risk persons: only about 14% of this subpopulation were negatively disposed to testing because of the potential for discrimination. This lower rate of concern about discrimination in comparison to, for instance, the study of Esplen et al. (2001), probably reflects differences in the American (or Canadian as in the Esplen study) and German health care systems. As Kaufert (2000) points out, there is a specific American relationship between health care, employment, and the health insurance industry, and that the interest of health insurances in data relating to the health status of the individual has increased exponentially. The German health care system is not built on the principle that “industry is entitled to access any information that increases its ability to predict the probability of disease” (Kaufert, 2000, p. 825).

In Germany, insurance companies currently deny any interest in genetic test results (Regenauer, 2001). However, our results not only show a difference in relation to American studies, but also to those from Europe. The study by Hietala et al. (1995) revealed that 59% of the Finnish population, 54% of the matched general population sample, and 40% of relatives of patients with AGU agreed that test results may lead to discrimination against disease gene carriers, which is clearly above the rates of agreement in our study samples. Again, there are differences in the health care systems between these two countries, and this may be the major cause for the obtained divergence in opinion. It is clear that this conclusion can only be tentative, and further comparative research should investigate the impact of health care delivery systems on attitudes toward genetic testing.

One interesting aspect of our data is that while the matched sample was more concerned with the issue of discrimination of disease gene carriers than the at-risk persons, concerns regarding the confidential use of test results were more pronounced in the sample of persons at risk for HNPPCC/FAP than in the matched general population sample. It seems as if the actual experience of having attended genetic counseling has reduced some concerns and increased others. This would imply that consumers of genetic counseling need to be fully informed about the further use of their data. It is critical to ensure that the consultant has been educated about the counseling process and its associated features through an appropriate genetic counseling protocol and consenting form. Transparency in this process should increase trust and well-being of consultants in this highly ambivalent and potentially life-turning situation. Research has

### Table 4. Reasons for Concern about Genetic Testing (Percentages)

<table>
<thead>
<tr>
<th>Question</th>
<th>Representative sample (n = 2,076)</th>
<th>Matched sample (n = 36)</th>
<th>Risk persons (n = 36)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>Somewhat</td>
<td>Much</td>
</tr>
<tr>
<td>10*</td>
<td>6.9</td>
<td>51.6</td>
<td>27.2</td>
</tr>
<tr>
<td>11*</td>
<td>6.7</td>
<td>49.0</td>
<td>29.0</td>
</tr>
<tr>
<td>12</td>
<td>7.2</td>
<td>44.6</td>
<td>25.3</td>
</tr>
</tbody>
</table>

Note: Percentages may not sum to 100 due to rounding error or not answered questions.

*p < 0.1 χ² test; df = 2 matched sample vs. risk persons.
shown that the issue of confidentiality is very important for individuals attending genetic testing (e.g., Benkendorf et al., 1997), and it is important to be cognizant of this personal need of the consumers of genetic testing services.

Another intriguing finding of our study is that persons at risk for HNPCC/FAP had less difficulty in taking stands toward attitude statements than the matched sample of the general population. This is indicated by a lower endorsement of “don’t know” responses by the at-risk persons. Although only a clue, this might be interpreted as indicating that genetic counseling fosters a clear-cut view of genetic testing. Because of the personal relevance of hereditary disease and their actual experience in having undergone genetic counseling at-risk persons might think more often about genetic testing, weigh the pros and cons carefully, and discuss the issue with other persons. Thus, they might more easily develop a clearer attitude toward gene tests than unaffected individuals. The higher endorsement of “don’t know” responses of our matched sample might reflect the difficulties in taking a clear view toward an abstract issue. Perhaps, it also indicates a lack of interest in this issue, or more scepticism. As Matsuenger and Angermeyer (1996) have demonstrated, the endorsement of the “don’t know”-response category indicates a more critical view of the issue under study. This would underline our general conclusion that our sample of at-risk persons holds a more positive view of genetic testing. However, we acknowledge that “don’t know” responses can imply different meanings (see Turner and Michael, 1996), and we cannot decide definitely which of the variety of meanings of this response is most appropriate for our data.

So far, we have supposed that participation in genetic counseling might have influenced general attitudes toward genetic testing in the sample of at-risk persons. Of course, another possible explanation for our results is that only at-risk persons who already had a positive attitude toward genetic testing attended genetic counseling. This would raise questions about any impact of the genetic counseling sessions on general attitudes toward gene tests. In fact, research has shown that there exists a self-selection bias in participation in genetic testing for HNPCC. Those who undergo genetic testing are more likely to be employed (Aktan-Collan et al., 2000), have a higher formal education, have less depressive symptoms (Lerman et al., 1999), indicate an increased risk perception, and have a higher perceived self-efficacy in coping with unfavorable results (Codori et al., 1999). Moreover, Vernon et al. (1999) have shown that the intention to learn genetic test results was predicted by a positive view of gene tests. Individuals who thought that the benefits of genetic testing outweigh the negative aspects were more likely to want to know about their carrier status.

In contrast with other hereditary diseases, a self-selection bias due to existing favorable attitudes toward genetics may be especially likely in the case of HNPCC/FAP, because of the fact that specific test results lead to real options for disease prevention and early treatment. Knowing about these options may create hope and optimism in many individuals, thus impacting positively on attitudes toward genetic testing, which, in turn, contribute to the likelihood of attending genetic counseling.

Clearly, the results and conclusions of our study are limited by the small sample size of at-risk persons and the fact that precounseling data concerning attitudes toward genetic testing was not available. Yet, this study raises an important question, namely the issue of attitude change after genetic counseling and/or genetic testing, which has largely been ignored in research on attitudes toward genetic testing and should be investigated in further studies. Furthermore, the response category “don’t know” turned out to be quite problematic because some significant results were due to the high percentage of “don’t know” responses and because it was impossible to decide which of the variety of meanings for “don’t know” fitted our data best. However, in the absence of in-depth data on the meaning(s) of this response in our sample, we follow the argument of Matsuenger and Angermeyer (1996) who analyzed “don’t knows” in a large representative survey and concluded that endorsement of this response category reflects a more critical view of the study’s issue.

Finally, a short reference to the Finnish study from which we borrowed our questionnaire, is indicated (Hietala et al., 1995; Jallinoja et al., 1998). Generally speaking, there are some similarities in attitudes toward genetic testing in the German and Finnish population, but the approval of genetic testing is higher in Finland than in Germany (see Berth et al., 2002a). The most striking difference between these two countries is the enormously higher endorsement of “don’t know” responses in Germany as compared to Finland. Our study does not allow us to draw firm conclusions about the true causes of this divergence. Yet it illustrates the importance of conducting comparative cross-cultural research. There are, for example, continuing efforts at coordination and collaboration in the European Union (see Ratzel, 2000; van Herten and van de Water, 2000; Chadwick et al., 2001) to produce between-country studies that provide comparable data on the same issue. This is especially true for the promising, yet complex and multifaceted, issue of gene technology.

ACKNOWLEDGMENT

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ANNOTATION

This research was presented at the International Meeting on Psychosocial Aspects of Genetic Testing for Hereditary Breast and/or Ovarian Cancer (HBOC) and Hereditary Non-Polyposis Colorectal Cancer (HNPCC), 27.-28.05.2001, Frankfurt/Main, Germany.

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