Risk Communication in Genetic Testing for Cancer Susceptibility

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Risk communication is an integral part of genetic counseling and testing for cancer susceptibility. This paper reviews the emerging literature on this topic. Three relevant aspects of risk communication are addressed: communication of individual risk, communication of the risks inherent in genetic testing, and family communications related to risk. These studies suggest that (a) most individuals with some family history of cancer, including those at low to moderate risk, overestimate their personal cancer risk; (b) awareness of the risks of genetic testing is limited; (c) decision making about genetic testing is influenced strongly by exaggerated perceptions of personal cancer risk and less so by perceptions of the risks of genetic testing; (d) perceptions of personal risk of cancer are resistant to standard education and counseling approaches; (e) psychologic distress and coping processes influence the processing of risk information and subsequent decision making in genetic testing; and (f) family influences play an important role in risk awareness, genetic testing decisions, and outcomes. To study these issues further, new theoretical models and measures of risk perceptions need to be developed. Both observational and experimental methods should be used to examine both the content and process of risk communication in cancer genetic counseling and testing. Emotional, familial, and sociocultural influences on the risk communication process require special attention. [Monogr Natl Cancer Inst 1999;25:59–66]

The isolation of several major cancer susceptibility genes has made it possible to provide predictive genetic testing for cancer susceptibility. Individuals who inherit mutations in these susceptibility genes can be identified years before cancer develops and can engage in appropriate risk-management strategies. Standard protocols for genetic counseling and testing rely heavily on risk communication to convey information about personal and familial cancer risk and to counsel participants about the risks of genetic testing (1,2). For example, pretest counseling sessions focus on the cancer family history and on individual risk status, including the likelihood that the individual has inherited a cancer-predisposing mutation. Another essential element of pretest counseling is a discussion of the risks of genetic testing. Central features of posttest counseling include discussion of the interpretation of the genetic test result, of individual and family risks for developing cancer, and of options for risk management.

Accurate risk comprehension among participants in genetic counseling programs may be critical to their decision making about whether to have a genetic test and, among those who test positive, to their decision making about risk management. Therefore, risk perception and risk communication related to cancer genetics have become active areas of investigation in recent years. Of particular relevance are questions concerning how individuals and families perceive their inherited risks of cancer and how well they understand the risks of genetic testing. Also key are questions concerning the relationship of risk perceptions to genetic testing decisions and the effect of genetic counseling on risk comprehension.

The objective of this paper is to review the emerging data on risk perception and risk communication in genetic counseling and testing for cancer risk. First, we discuss the unique aspects of genetic testing for cancer susceptibility that distinguish this work from other research on risk communication and cancer. Next, we review existing literature on risk perception and communication in cancer genetic counseling and testing. Three relevant aspects of risk communication are addressed: communication of individual risk, communication of the risks inherent in genetic testing, and family communications related to risk. Because this field of research is in the very early stages, we include in our discussion research on risk communication in persons with a family history of cancer, as well as studies of genetic counseling and testing. An important extension of risk communication research, concerning the role of emotion in risk perception and risk communication, is discussed in the following section. Last, we suggest topics for future research to further our understanding in this area.

UNIQUE ASPECTS OF GENETIC TESTING

Inherited Genetic Risk Is Imposed

Unlike acquired cancer risk factors, such as unhealthy diet, physical inactivity, and smoking, exposure to an inherited mutation cannot be altered by the at-risk individual. In addition, the fact that individuals bear a substantial risk of cancer through no choice of their own may exacerbate a sense of fatalism regarding their future health (3). Experiments designed to examine psychologic reactions to notification of imposed risk factors (as opposed to risk factors resulting from the individual’s behavior) have shown a tendency for individuals to minimize the perceived seriousness of the risk (4). Such distortions of risk information may reduce distress in the short term (5), but a sense of fatalism may also diminish motivation to engage in healthy behaviors (6). Individuals may also exaggerate risk-factor information, as documented below in studies of genetic testing for cancer susceptibility (7).

Efficacy of Risk Reduction Strategies Is Unproven

When carriers of cancer-predisposing mutations are advised about options for cancer screening and risk reduction, they also should be informed that these methods have not yet been proven...
Within 10 percentage points of their actual risk, and only 2% of women reported subjective risk estimates that were lower than 10%. In a study of relatives of breast cancer patients who were at low to moderate risk for colon cancer, the health care provider contact the relatives. Thus, the individual’s communication of his or her test result and risk status is necessary for other family members to have access to testing. Although family members may or may not elect to participate in genetic counseling and testing themselves, the knowledge of their relative’s test result may help to clarify their personal risk status. Family communication can also have important effects on psychologic well-being, as has been shown among families coping with other forms of inherited illness (18). As suggested below, family variables are likely to moderate the effect of risk communication on decisions about cancer testing and on quality of life in persons who are tested.

**Genetic Testing Has Implications for Families**

Inherited risk for cancer is shared within families. Typically, genetic testing for cancer risk is initiated with an affected individual in the family. If a known risk-conferring mutation is identified, then other relatives can be tested for this mutation. A common process, employed in most clinical research settings, is to discuss with the individual the implications of his or her test result for other family members (17). This individual is then given the option to contact his or her relatives directly or to have the health care provider contact the relatives. Thus, the individual’s communication of his or her test result and risk status is necessary for other family members to have access to testing. Although family members may or may not elect to participate in genetic counseling and testing themselves, the knowledge of their relative’s test result may help to clarify their personal risk status. Family communication can also have important effects on psychologic well-being, as has been shown among families coping with other forms of inherited illness (18). As suggested below, family variables are likely to moderate the effect of risk communication on decisions about cancer genetic testing and on quality of life in persons who are tested.

**Individual Risk Perception in the Genetic Counseling Context**

**Association of Perceived Risk to Actual Risk**

One of the most consistent findings in behavioral research on cancer risk is that a surprising number of people overestimate their risk for cancer and lack knowledge of risk factors and genetic inheritance. This finding has been documented in studies, ranging from population-based surveys about genetic testing (19) to research on hereditary cancer families (20). An earlier study (21) examined risk perceptions among 200 first-degree relatives of breast cancer patients who were at low to moderate risk of breast cancer. Their perceived risk of breast cancer, rated on a 1–100 scale, was compared with a lifetime breast cancer probability calculated on the basis of the Gail Model (22). Less than 10% of women reported subjective risk estimates that were within 10 percentage points of their actual risk, and only 2% underestimated their risks. About two thirds of women rated their risk higher than the highest possible risk score that could be achieved for someone in their age group. Overall, the average calculated risk for these women was about 14%, compared with an average perceived risk of breast cancer of about 50%. A more recent study (23) classified women from a random-mailed survey into four family history groups (none, minimal, moderate, or strong) on the basis of the model by Claus et al. (24). Over one fourth of women with no family history of breast cancer reported that they had a lifetime risk of breast cancer greater than or equal to 25%. Women in all groups overestimated their lifetime risks. In another study of diverse groups of women with a family history of breast cancer, perceived risks of breast cancer ranged from 3.7-fold to 4.5-fold higher than their actual breast cancer risks (25). Similar findings have been reported for relatives of colon cancer patients (26). In this study population, the average perceived lifetime risk of colon cancer was greater than 50%, despite the fact that the majority of participants had only one affected first-degree relative.

Exaggerated perceptions of personal risk are not limited to lower risk populations. In a study of members of hereditary breast-ovarian cancer families (20), perceived risks of having an altered BRCA1 gene were higher than their actual risk on the basis of the cancer family history. For example, about one third of unaffected females with an affected first-degree relative believed that their risk of inheriting a mutation was 75% or greater, compared with an actual risk of 50%. Although women generally had higher perceived risks than male family members (despite the fact that the probabilities of inheriting a mutation are unaffected by gender), about one half of men without an affected relative reported that their risk was 50% or greater. In a more recent study (27), 60% of women overestimated their risks of being a BRCA1 or BRCA2 mutation carrier. The average difference between perceived risk of being a carrier and estimated risks calculated by use of a risk probability model (28) was 32%.

**Effect of Cancer Risk Communication on Perceived Risk**

How effective are education and counseling in altering exaggerated cancer risk perceptions? To date, this question has been addressed only in the context of breast cancer risk counseling programs, and data on genetic testing for cancer risk are not yet available. In a prospective study, Alexander et al. (29) studied 59 women participating in the Breast Cancer Prevention Trial of tamoxifen for chemoprevention of breast cancer. Similar to the previously cited study by Lerman et al. (21), women’s average perceived lifetime breast cancer risk was about 50%. However, among 29 women who received individualized risk information (based on the Gail Model) and returned for a follow-up visit, the average perceived risk had dropped to 25%. Although the reduction in risk overestimation was impressive, this figure still greatly exceeded participants’ actual risks (15%).

In a retrospective study conducted in the U.K., Lloyd et al. (30) compared the risk perceptions of 62 breast cancer risk counseling participants with 62 matched attenders of a general health clinic (controls). Participants in risk counseling perceived themselves to be at greater risk of breast cancer than control subjects; however, this could be the result of a bias in terms of self-selection to risk counseling programs. Despite participation in risk counseling based on the Cancer and Steroid Hormone model, two thirds of women could not provide accurate assessments of their lifetime breast cancer risks. Using a prospective
study design, this research group (31) reported on changes in breast cancer risk perceptions following risk counseling among 282 women with a family history of breast cancer. Overall, 9% of women had accurate risk perceptions at baseline, compared with 31% following counseling and 17% at 1-year follow-up. Thus, while there was a small improvement in the accuracy of perceived lifetime risk, the majority of women continued to overestimate their risks. Furthermore, the initial improvement in risk estimation was not maintained 1 year later.

Two studies in the literature used a randomized trial design to evaluate breast cancer risk communication efforts. In one of these studies (21), 200 women were randomly assigned to receive individualized breast cancer risk counseling, based either on the Gail Model or on general health counseling (control group). Although the concordance between subjective and objective breast cancer risk was improved in the risk counseling group, compared with the control group, the magnitude of this effect was small. Similar to the results of Watson et al. (31), about two thirds of subjects in both groups continued to overestimate their risks substantially following both types of counseling. Another study (32) tested the provision that an audiotape of the session would improve recall of risk information. One hundred fifteen women with a family history of breast cancer were randomly assigned to receive breast cancer risk counseling either with or without an audiotape. The results showed that provision of the audiotape significantly reduced worries about cancer but did not influence the accuracy of perceived risk.

**Perceived Personal Risk and Decision Making About Genetic Testing**

Initial studies, conducted before the availability of genetic testing, explored the association of perceived risk with intentions to have a genetic test for cancer. Although these studies used hypothetical scenarios to assess interest in testing and therefore may not be applicable to actual test use, the data on risk perception are of interest. Studies of intentions to have a genetic test for breast cancer (20,27,33) have documented universally high interest in testing, with about 70% or more respondents reporting positive intentions to be tested. In these studies, perceived risk, but not actual risk, was found to correlate with genetic testing intentions. Similarly, Lipkus et al. (34) found that concern about breast cancer was a more powerful predictor of testing intentions than knowledge of risk factors or actual risk status based on family history.

Similar findings have been reported for colon cancer genetic testing. Interest in genetic testing has been expressed by more than 80% of the respondents to a statewide survey (35), about 90% of colon cancer patients (36), and up to 77% of first-degree relatives (37–39). In a study by Petersen et al. (39), interest in genetic testing was found to be independent of actual risk status based on the number of affected first-degree relatives; however, Glanz et al. (38) found that both actual and perceived risk correlated with testing intentions.

These studies have been extended by others that examine the determinants of actual use of genetic counseling and testing. For example, Geller et al. (40) found that, among women at high risk for breast cancer, genetic counseling attendees had higher levels of perceived risk. In the setting of genetic testing for colon cancer, perceived risk of cancer, but not actual risk, was found to predict uptake (26). It is also important to note that rates of interest in genetic testing reported in studies using hypothetical scenarios (20,27,33) greatly exceed actual test uptake in these studies.

Decision making regarding BRCA1 testing was examined in a study (41) of 400 low-to-moderate risk women with a family history of breast or ovarian cancer. The purpose of the study was to test the impact of genetic education and counseling on knowledge, perceived risk, and intention to be tested. Participants were randomly assigned to receive standard pretest education for BRCA1 testing, pretest education plus counseling, or a wait-list control. The education approach reviewed information about personal risk factors; inheritance of cancer risk; and the benefits, limitations, and risks of genetic testing. The education-plus-counseling approach included this information and addressed psychosocial issues, including personal experiences with cancer and the potential psychologic and social effect of testing. At 1-month follow-up, both the education and education-plus-counseling groups exhibited superior knowledge about cancer risk and genetic testing than did the control group. Both counseling groups also showed reductions in perceived risk of having a BRCA1/2 mutation; however, the magnitude of these effects was small. Moreover, neither education approach produced changes in intentions to be tested. Thus, genetic counseling may not greatly diminish perceptions of cancer risk or interest in testing, even among persons at low risk of developing cancer.

Whereas data on individual risk perception and communication are still emerging, the studies described above lead to a few tentative conclusions. First, inflated perceptions of inherited risk of cancer are pervasive in individuals at all levels of risk and for different cancer types. Second, these exaggerated risk perceptions appear to drive testing decisions to a greater degree than does actual risk status. Third, and perhaps most important, perceptions of cancer risk have been refractory to education and counseling.

**COMMUNICATION OF THE RISKS OF GENETIC TESTING**

Although perceived risk of cancer is an important component of genetic counseling, information about the benefits and risks of testing may be more essential for informed decision making (42). Despite this finding, there has been relatively little empirical research on this topic. Much of what we know about the perceived risks of genetic testing is derived from studies of attitudes and intentions to be tested rather than from studies of actual participants in genetic testing programs. Studies of potential test participants generally assess the perceived importance of the risks and benefits of genetic testing, based on theories of health behavior (43). For example, Jacobsen et al. (44) examined the association of perceived risks and benefits of testing with intentions to have a BRCA1 test among women at risk for familial cancer. The measure of testing benefits included statements relating to the potential positive outcomes of testing (e.g., reassurance, information to facilitate surgery decisions, etc.). A measure of testing risks included statements about the possible negative outcomes (e.g., increases in worries about cancer with a positive test result, insurance discrimination and stigmatization, and negative reactions in family members). As predicted, women who had higher ratings of the risks of genetic testing, relative to their ratings of the benefits, were less likely to intend to be tested. Likewise, Geller et al. (40) demonstrated that fear of stigma deterred participation in genetic counseling among women at risk for breast cancer. However, in a study of colon cancer patients who had provided a blood sample (36), the
perceived benefits of testing had a stronger influence on desires to be tested than did perceptions of the risks of testing.

The role of perceptions of genetic testing risks in actual testing decisions was examined in a prospective cohort study of BRCA1/2 testing (45). Overall, the risks of genetic testing were rated as much less important than the benefits. After controlling for demographic and medical factors, uptake of genetic testing was associated with the perceived benefits of testing but not with the perceived risks. This finding underscores the importance of emphasizing communication about the risks of genetic testing to a greater degree in informed consent encounters.

Although these observational studies shed some initial light on the role of perceived risks of genetic testing, experimental designs can provide a stronger test of the effect of risk communications. In the randomized trial of pretest education approaches described above (41), standard education that included the risks of genetic testing had no more effect on participants' perceived risks of genetic testing than the wait-list control condition. However, the education-plus-counseling approach did lead to statistically significant, but modest, increases in perceived risks of testing. This finding suggests that discussion of the psychosocial aspects of genetic testing may have made the risks of testing, especially the psychologic risk, more salient to participants. However, as noted above, neither education nor education plus counseling appeared to influence genetic testing decisions.

Thus, in contrast to the studies showing the overestimation of personal risk of cancer, the results of the above studies show that the risks of genetic testing itself appear to be underestimated. Moreover, perceptions of genetic testing risks exert relatively little influence on genetic testing decisions. Thus, other individual and family factors must exert important influences in the decision-making process.

### Risk Communication in Families

One of the most pressing, yet least studied, issues in genetic testing for cancer susceptibility concerns family communication of cancer risks (46). As described above, inherited risk is shared within families, and the risk status of one family member has implications for the others. Thus, familial risk communication is a potentially important determinant of decision making and testing outcomes. This is supported by studies showing that the desire to have genetic testing for colon cancer risk is related to the desire to help family members (36) and to levels of family support (38). For high-risk women considering genetic testing for breast cancer risk, having a daughter predicts participation in genetic counseling (40). In this study, participants cited the desire to help relatives as the factor that motivated them to involve other relatives in testing.

Data are beginning to emerge with respect to communication of genetic testing results within families. Green et al. (47) found that 88% of breast–ovarian cancer genetic counseling participants shared their consultation summary letter with at least one first-degree relative. In a study of members of hereditary breast cancer families participating in BRCA1/2 testing, 81% of carriers and 85% of noncarriers who had sisters reported that they shared their test results with them (48). Relatively fewer carriers and noncarriers shared results with a brother (60% and 63%, respectively). A higher rate of communicating test results to females than to male relatives was also found by Green et al. (47). This finding may be attributable to the belief that risk information about breast cancer is more relevant to females than to males. Surprisingly, 37% of carriers and 35% of noncarriers reported that they communicated their test results to a child under age 13 years. Although most individuals may disclose their genetic test results to family members, many are reluctant to have clinicians communicate their results to others, at least not without their explicit consent. In a survey of attitudes about BRCA1/2 testing among relatives of breast cancer and ovarian cancer patients, over 80% of respondents reported that health care providers should not disclose their test results to immediate family members without their written consent (49).

Risk communication within families can have important implications for the psychologic well-being of family members. In a preliminary study of participants in a clinic-based BRCA1/2 testing program (50), BRCA1/2 carriers who communicated their test results to their sisters exhibited a small decrease in psychologic distress, whereas those who did not disclose their results showed a small increase. In the first study to examine the psychological effects of BRCA1 test results among family members, Smith et al. (51) found that individual’s short-term reactions to testing depended on their siblings’ test results. Specifically, among female mutation carriers, psychologic distress was higher among those who were the first in their families to be tested and among those who had siblings who tested negative. For males, psychologic distress was elevated for those who tested negative but who had siblings who all tested positive. The data are consistent with the notion of “survivor guilt” among males, a phenomenon frequently discussed by clinicians but rarely studied empirically. Unfortunately, these studies did not examine the content or process of risk communication in families. Nonetheless, they underscore the point that family communication of risk and its consequences are likely to have an important influence on the decisions and adjustment of individuals and their family members.

### Role of Emotion and Coping in Risk Perception and Communication

Both theory and research suggest that emotional factors can modify the cognitive processing of risk-related information when an individual is faced with a personally relevant health threat (4,52). This modification is especially common in risky decisions that are made under emotional stress (53). Given the possibility of receiving very bad news, one would expect the genetic testing situation to be particularly stressful and distressing. According to Janis and Mann (53), stress (or distress) interferes with one’s ability to consider the most salient features of the situation and to deliberate carefully about the pros and cons of alternate options. Previous studies provide some support for this conceptualization. In the laboratory setting, anxiety and stress have been found to lead to a narrowing of focus and to impulsive or careless decision making (54,55). In the randomized trial of breast cancer risk counseling described above, the intervention was not successful in improving risk comprehension among participants with higher levels of breast cancer-related distress (21).

In the genetic testing context, psychologic distress appears to have both direct effects on decision making and effects that interact with risk perceptions. In the studies described above, worries about cancer were positively related to interest in genetic testing for breast cancer (25) and colon cancer (36,38,39). Cancer-related distress has also been shown to motivate actual use of
genetic testing in high-risk populations. Among members of hereditary breast cancer families, those who reported more frequent intrusive thoughts and worries about cancer were about three times more likely to obtain BRCA1/2 testing (56). Interacting effects of cancer worries and risk perceptions on genetic test use were reported by Codori et al. (26). In this study of individuals at risk for colon cancer, perceived cancer risk predicted use of testing for hereditary nonpolyposis colorectal cancer only in persons who also had high levels of worries about cancer.

The positive association between cancer-related distress and test uptake provides an interesting contrast to findings related to distress and use of predictive testing for Huntington’s disease (HD), a progressive neurodegenerative disease. van der Steen-straten et al. (57) found that, among individuals at risk for HD, those who were distressed were significantly less likely to participate in genetic testing. Specific distress symptoms that predicted nonparticipation included pessimism, preoccupation with HD, and anxiety about adverse outcomes of receiving HD test results. Thus, HD-specific distress and cancer-specific distress appear to exert opposite effects on use of genetic testing. To understand and interpret this discrepancy, one needs to consider key differences between HD and breast–ovarian cancer. Unlike breast–ovarian cancer, a positive genetic test result for HD is associated with a 100% probability of disease. In addition, there are no strategies available to alter the likelihood or course of HD. Thus, disease-specific distress may promote genetic testing only if this action is perceived as offering the potential for risk reduction or altering the course of the disease.

Whereas the studies of cancer-specific distress show a positive relationship with test intentions and uptake, generalized distress may exert different effects. In a study of members of families with hereditary nonpolyposis colorectal cancer (58), depression symptoms were associated with lower rates of test use. In fact, among women, those who reported depression symptoms were about four times less likely to be tested. In comparison with worries about cancer, global distress symptoms may reflect or generate a sense of fatalism about the future that may diminish motivation for health-protective behaviors such as genetic testing.

Thus, the specific effects of distress and emotional factors on genetic testing decisions and outcomes may depend on the level and type of distress and on beliefs regarding the potential for controlling risk. When an individual perceives the outcomes as controllable (i.e., risk can be reduced), cancer-specific distress may motivate active coping strategies, including use of genetic testing. This has been reported for the use of mammography screening in women at risk (59). However, global distress, a perceived lack of control, or both may generate aversion of genetic testing. This relationship may generate a vicious cycle in which distress generates avoidance that, in turn, generates more distress. This finding is supported by a study of the role of baseline distress in adjustment following BRCA1/2 testing in hereditary breast cancer families (60). In this study, individuals who had high levels of cancer-related distress at baseline but declined to have BRCA1/2 testing reported the highest levels of depression symptoms at 6-month follow-up. Depression symptoms were reported more frequently in these individuals than in relatives who had received positive test results. Post-hoc analyses suggested that these test decliners were motivated to be tested to reduce levels of distress; however, because of fears of discrimination and other adverse outcomes of testing, they avoided testing. Thus, their cancer risk status remained uncertain, and depression levels increased over time. This finding is consistent with previous studies of HD (61).

**IMPLICATIONS FOR FUTURE RESEARCH**

These initial findings point to the critical challenges faced by educators and counselors who wish to impart more accurate risk information in genetic testing to enhance informed decision making. An important next step in this line of research will be to apply new theoretical models both to explain these findings and to guide the next set of studies on risk communication. In addition, it is time for investigators to focus on the content and process of communication with specific relevance to genetic testing and to extend this work beyond studies of intentions to research on actual testing decisions and outcomes. Although prospective cohort studies of participants in genetic testing would be informative, there also is a need for theoretically guided experimental studies to further our understanding. The discussion below highlights a few specific suggestions for future research in this area.

A critical need for this research domain is the development and validation of better measures of risk perception. A variety of measures are currently in use, including qualitative assessments (e.g., “compared with other women your age, would you say your risk is much lower, lower, about the same . . .?”) and quantitative assessments (e.g., “on a scale from 0 to 100, in which 0 equals no chance of getting breast cancer and 100 means you definitely will get it, which number represents the chance that you will get breast cancer someday?”). Qualitative assessments of comparative risk are problematic because the meaning of “lower” or “higher” risk to a given woman is uncertain. Also, because numeric risk figures (or ranges) generally are provided in genetic testing, qualitative assessments may be less sensitive for measuring the effect of counseling on risk comprehension. Whereas an absolute quantitative assessment on a 0–100 scale is appealing because it is consistent with probability information presented by counselors, this assessment is problematic. Two studies that used this measure (21,29) both found an average perceived lifetime risk of about 50%. However, anecdotal reports of our study subjects (21) suggest that this is interpreted to mean “a 50–50 chance—maybe I’ll get it and maybe I won’t,” thus reflecting uncertainty rather than a specific probability.

Whereas the above measures of risk focus on lifetime cancer risks, it may be more useful to use measures of more immediate relevance in the genetic testing context. For example, an important component of risk in decision making about whether to have a genetic test is the likelihood that a person has an inherited mutation. Such methods have been used in some studies (20,27), although their sensitivity to education and counseling has not yet been tested. In addition, because posttest counseling includes communication of age-specific penetrance (i.e., the likelihood that a mutation carrier will develop cancer by a particular age), risk measures in age increments may be more applicable (e.g., the chances that you will develop breast cancer in the next 5 years). Work described elsewhere in this monograph (62) suggests that graphical displays of risk information may also provide a promising alternative to verbal risk communication and assessment.

Experimental study designs would provide an optimal approach to evaluate the merits of alternative methods for risk
communication and for the assessment of risk comprehension. Investigators should consider using analogue or laboratory study designs. These methodologies have been used effectively to manipulate different components of risk-related information (e.g., test validity, time frame for disease onset, disease prevalence, and residual risks) and to evaluate the effects on risk comprehension and health-related decisions (63). A more thorough examination of mental representations of inherited cancers would also advance understanding of the relationships among risk perception, health beliefs, emotional processes, and behavior (64). Experimental designs could be adapted for use in the clinical setting; however, there would be somewhat less flexibility. Whereas it may not be feasible or ethical to manipulate the content of risk communication in genetic counseling, the format could be varied. Observational studies of genetic counseling could also examine the processes and content of risk communication and participant–counselor interactions as well as the effect of these variables on genetic testing decisions and outcomes. Innovative educational approaches, such as CD-ROM technology (65), which allow participants to select the amount and type of information desired, could also be used to determine participants’ informational preferences and needs. Such research could highlight factors of importance to risk communication that could subsequently be evaluated in experimental studies.

Another important, but understudied, area of risk communication and genetic testing concerns the influence of contextual factors. Specific contextual influences of importance in risk communication include family factors and sociocultural factors. Some preliminary research on family influences is described above; however, much additional work is needed. Although we have learned that a majority of genetic testing participants communicate their risks to other family members, we know very little about the content, process, and impact of these communications. For example, what factors influence decisions to communicate risk information to some relatives and not to others? What level of detail about test results and personal risk is communicated, and how accurate is this information? How do family communications about cancer risk and genetic testing encourage or discourage other family members from being tested? To address these and other questions about family influences in risk communication and genetic testing, better measures of family communications and interactions are needed (66). In addition, investigators are encouraged to use direct observation and coding methods developed for marital and familial interaction research (67–69).

Finally, much of the research on genetic testing for cancer susceptibility has been conducted with predominantly Caucasian populations. The few available studies of other ethnic groups, mostly African-Americans, highlight differences in risk comprehension. For example, in a series of studies, Hughes et al. (70) found that, compared with Caucasian high-risk women, African-American women with a family history of breast cancer were less likely to perceive themselves as being at high risk, had more favorable attitudes about genetic testing for breast cancer and less awareness of the risks (71), had different beliefs about test result disclosure to family members (49), and were more responsive to the effects of pretest counseling interventions (72). Unfortunately, we know very little about the specific cultural beliefs that may underlie these differences. Research in more diverse populations is critical to address these issues.

**SUMMARY AND CONCLUSIONS**

As shown from this review, with some exceptions, the initial studies of risk communication in the genetic testing context have been largely descriptive. These studies suggest that (a) most individuals with some family history of cancer, including those at low to moderate risk, overestimate their personal cancer risk; (b) awareness of the risks of genetic testing is limited; (c) decision making about genetic testing is influenced strongly by exaggerated perceptions of personal cancer risk and less so by perceptions of the risks of genetic testing; (d) perceptions of personal risk of cancer have not been greatly influenced by standard educational approaches; (e) psychologic distress and coping processes influence the processing of risk information and subsequent decision making in genetic testing; and (f) family influences play an important role in risk awareness, genetic testing decisions, and outcomes.

These findings also point to directions for future research. To develop a better understanding of risk communication in cancer genetic testing, new theoretical models and measures of risk perceptions need to be developed. Both observational and experimental methods should be used to examine both the content and the process of risk communication. Emotional, familial, and sociocultural influences require special attention. Finally, an improved understanding of risk communication in diverse populations is critical to develop genetic counseling methods that are most effective and most sensitive to the perspectives and backgrounds of individual participants.

**REFERENCES**


(12) Lerman C, Glanz K. Stress, coping, and health behavior. In: Glanz K,


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**Note**

Drs. Croyle and Lerman are joint first authors of this manuscript. The order of their names is entirely arbitrary.