ORIGINAL ARTICLE

Controversies in Communication of Genetic Risk for Hereditary Breast Cancer

Amy MacKenzie, MD,* Linda Patrick-Miller, PhD,† and Angela R. Bradbury, MD‡

Department of Medicine, Fox Chase Cancer Center, Philadelphia, PA; †Division of Behavioral Sciences, Teh Cancer Institute of New Jersey, New Brunswick, NJ; and ‡Department of Clinical Genetics, Fox Chase Center, Philadelphia, PA, USA

■ **Abstract:** Increased availability and heightened consumer awareness of "cancer genes" has increased consumer interest in, and demand for breast cancer risk assessment, and thus a pressing need for providers to identify effective, efficient methods of communicating complicated genetic information to consumers and their potentially at-risk relatives. With increasing direct-to-consumer and -physician marketing of predictive genetic tests, there has been considerable growth in web- and telephone-based genetic services. There is urgent need to further evaluate the psychosocial and behavioral outcomes (i.e., risks and benefits) of telephone and web-based methods of delivery before they become fully incorporated into clinical care models. Given the implications of genetic test results for family members, and the inherent conflicts in health care providers' dual responsibilities to protect patient privacy and to "warn" those at-risk, new models for communicating risk to at-risk relatives are emerging. Additional controversies arise when the at-risk relative is a minor. Research evaluating the impact of communicating genetic risk to offspring is necessary to inform optimal communication of genetic risk for breast cancer across the lifespan. Better understanding the risks and benefits associated with each of these controversial areas in cancer risk communication are crucial to optimizing adherence to recommended breast cancer risk management strategies and ensuring psycho-social well-being in the clinical delivery of genetic services for breast cancer susceptibility. ■

The discovery of the role of *BRCA1/2* mutations in the development of hereditary breast and ovarian cancer, and the development of a clinical test for the identification of those mutations holds great promise for reducing the risk of hereditary breast and ovarian cancer. Although professional societies have provided recommendations for pre- and post-test counseling by health care practitioners with specialized genetics training, there are aspects of genetic testing for hereditary cancer that remain controversial. Increased availability and heightened consumer awareness of "cancer genes" has increased consumer interest in, and demand for hereditary cancer risk assessment, and thus, a pressing need for providers to identify effective, efficient methods of communicating complicated genetic information to consumers and their potentially at-risk relatives. Optimal outcomes of communication of genetic test results include adherence to recommended risk management strategies and maximization of psycho-social well-being. This requires not only the effective communication of risk information, but also an understanding of the consumers' translation of that information into personalized perceptions of risk of disease, benefits of interventions and the bio-psychosocial factors that mediate that process. Other concerns include the transfer of genetic risk information to at-risk relatives, including providers' obligation regarding "duty to warn" at-risk relatives. When the at-risk relative is a minor, additional controversies arise regarding the timing of disclosure of familial risk, and the appropriateness of minors' testing for adult-onset hereditary cancers. These concerns remain the subjects of ongoing debate and necessitate further empiric research to inform evidence-based guidelines.

Address correspondence and reprint requests to: Angela R. Bradbury, MD, Director, The Margaret Dyson Family Risk Assessment Program, Fox Chase Cancer Center, 333 Cottman Ave., Philadelphia, PA 19111, or e-mail: angela.bradbury@fccc.edu.

DOI: 10.1111/j.1524-4741.2009.00800.x

The Breast Journal, Volume 15 Suppl. 1, 2009 25–32

PROVIDER COMMUNICATION OF GENETIC RISK INFORMATION TO PATIENTS

Effective counseling of patients undergoing *BRCA1/2* genetic testing includes risk communication, informed consent, and psychosocial support (1–7).

The American Society of Clinical Oncology and other professional societies have recommended that predictive genetic testing be paired with pre- and post-test counseling, to provide patients adequate information to fully understand and process the implications of their test results and to optimize informed consent (1,8–10). Given the complexity of genetic information, the *potential* for false reassurance, the *potential* social and psychological risks, and the limitations of available interventions to modify an identified increased risk for cancer, communication of predictive genetic information in oncology has *traditionally* been conducted in-person by a health care professional with training in clinical genetics. Despite these recommendations, there is limited data supporting the effectiveness of traditional counseling models to impact preventive health or risk-reduction behaviors. Studies to date show that genetic counseling improves knowledge, has variable impact on general anxiety and cancer-specific worry, has no impact on depression or health-related quality-of-life, and most significantly, no impact on risk perception, a consistent predictor of risk-reduction behaviors (11). In a 21 study meta-analysis evaluation, the only longitudinal study evaluating behavioral outcomes, genetic counseling failed to improve adherence to recommended surveillance (11).

Strategies to optimize communication of genetic risk information and genetic test results have shown variable results. Randomizing women with a family history of breast cancer to surgical consultation with or without genetic counseling demonstrated increased knowledge in the counseling group, but no difference between the groups in knowledge or satisfaction (12). Calzone et al. (13) found no difference in knowledge scores or levels of distress when comparing group and individual education and counseling sessions among high-risk patients, although all patients in both arms had a significant gain in knowledge that persisted for 12 months. A prospective study of genetic counseling reduced cancer-specific distress in high-risk women, but had no significant impact on health-related quality-of-life (14). Women randomized to standard genetic testing service or a community-based service all demonstrated increased understanding of genetics and significant reduction in cancer worry. Thus, studies evaluating modifications to traditional genetic counseling have demonstrated that adding informational content can improve cognitive, but not psychosocial outcomes, and adding psychological counseling can improve psychosocial outcomes, which consumers value more highly (15).

MODIFICATIONS TO TRADITIONAL MODELS OF COMMUNICATING GENETIC RISK TO PATIENTS

Although professional societies endorse pre- and post-test counseling with an experienced health care provider, access to genetics professionals is currently limited in many regions. As a result of direct-to-consumer and -physician marketing of predictive genetic tests, demand for genetic services for cancer risk assessment and predictive genetic testing are expected to potentially surpass the current availability of qualified cancer genetic specialists, suggesting a need for alternative methods of communication (1,16). At least five companies currently offer personal genome scans (23andMe, decode, Navigenics, GeneEssence, and SeqWright), and concordant ''streamlining'' of pre- and post-test counseling with little evaluation of these modifications to traditional counseling protocols (2). DNA Direct offers *BRCA1/2* genetic testing, entirely by telephone and the Internet. The insurance provider Aetna has paired with Informed Medical Decisions, a genetic counseling company, to provide ''Telephonic Genetic Counseling'' for a wide range of genetic services. Many physicians in community settings have incorporated genetic testing into their practices, often without the assistance of a genetics professional (17). Additionally, 39% of patients undergoing *BRCA1/2* testing in community settings receive genetic test results by telephone (18) and many genetic counselors report providing genetic test results to patients by telephone (19). Thus, commercial incentives of predictive genetic testing and the correspondent rapid application of direct-to-consumer and -physician marketing have been associated with modifications to traditional pre- and post-test counseling protocols prior to evidence of the efficacy and psychosocial impact.

Telephones, computers, and audiovisual equipment might be utilized to provide genetic services to populations where geographic or socioeconomic factors have limited the use and dissemination of genetic services. Electronic delivery of genetic services could decrease consumer burdens of scheduling and traveling to a clinical center, increase their perceived control, and decrease intimacy, which could foster communication for some individuals (20–24). Historically, prenatal genetic counselors have incorporated telephone communication into standard counseling services in the

Table 1. Potential Advantages and Disadvantages to Telephone Counseling for *BRCA1/2* Testing

Advantages
Extend clinical genetic services to rural and remote areas
Triage limited genetic services resources
Expedite genetic services for medical decision-making
Decrease costs
Increase consumer convenience and satisfaction
Disadvantages
Increase patient distress
Decrease provider capacity to read patients' nonverbal cues
Decrease provider capacity to provide emotional support
Increase potential for distractions and misunderstanding
Decrease satisfaction for some patients

communication of teratogen information (25,26). There are potential advantages and disadvantages of incorporating telephone communication into genetic services for breast cancer susceptibility (Table 1). There is emerging data suggesting that providers and patients recognize the potential risks of telephone communication of genetic risk information. Among consumers awaiting *BRCA1/2* test results, only 50% indicated they would be interested in receiving their results by telephone (27). Additionally, among individuals who received a positive test result, only 25% reported that they would have been interested in receiving their results by telephone (19).

Systematic evaluation of telephone communication as an alternative to in-person communication of components of genetic services is limited. Low and moderate risk women who received pre-test counseling, and may not have been candidates for genetic testing, reported equal satisfaction, similar declines in cancer worry and similar improvements in perceived risk as recipients of in-person counseling (22). Women enrolled in a phase II chemoprevention trial who self-selected to receive *BRCA1/2* results by telephone were as satisfied as those who selected to receive genetic test results in-person (28). A randomized comparison of telephone disclosure versus in-person disclosure of *BRCA1/2* test results among patients who participated in a clinical trial designed to evaluate group versus individual counseling (29) found no significant difference in knowledge, anxiety or satisfaction between the telephone communication and in-person communication arms. Although powered for equivalence, which was defined by a 0.6 SD change in pre–post scores, this range could allow inclusion of clinically significant differences between disclosure methods. Additionally, the study was not large enough to evaluate potential differences in outcomes by genetic test result (i.e., women who received a positive versus negative test result). Although each of these studies is informative, and suggest a potential role for telephone communication, they do not provide sufficient evidence of the efficacy, balance of good over harms, or equivalence to the current standard-of-care, in-person pre-test and post-test counseling. Thus, there is a need to further evaluate the psychosocial and behavioral outcomes (i.e., risks and benefits) of telephone counseling before telephone and web-based models of delivery become fully incorporated into clinical care models (9,30).

COMMUNICATION OF GENETIC RISK TO AT-RISK RELATIVES

Information discovered during genetic testing for hereditary cancers can affect family members as well as the patient undergoing testing. Given the confidentiality and privacy of medical and specifically genetic information, several professional societies recommend that patients who receive genetic test results be strongly encouraged to share this information with at-risk family members (31). However, these groups also acknowledge situations in which there may be sufficient competing claims for health care professionals to consider sharing genetic risk information with at-risk family members. Others maintain that a hereditary risk for cancer does not justify a breach of patient privacy, and providers only have an obligation to sufficiently communicate to the patient the implications of genetic risk for family members (1,32). At least one study suggests that respecting patient confidentiality may be most congruent with public expectations. Among 200 Jewish women, only 22% felt that a physician should seek at-risk relatives against a patient's wishes (33). Yet, health care professionals offering genetic services experience a conflict between maintenance of patient confidentiality and autonomy and potential harm to at-risk relatives (34). Surveys of medical geneticists indicate that many feel a distinct obligation to their patient's at-risk relatives, and up to 25% have considered warning relatives on at least one occasion (35,36). The legal precedent for health care professionals' duty to warn was set largely by Tarasoff v. Regents of the University of California (37). In this case, a psychiatrist who had sufficient information that a student was in imminent danger at the hands of a patient, failed to warn her. The legal duty to

"warn" at-risk family members in the case of hereditary cancers is less clear. In the case of Pate v. Threkel, the court ruled a physician had the duty to warn the patient of the potential of an increased risk to relatives but not an obligation to directly inform relatives (38). However, in Safer v. Pack an intermediate appellate court in New Jersey court ruled the physician should have taken steps to warn immediate relatives of the familial risk of colon cancer (39).

Given the conflict between patient privacy and informing at-risk relatives, conveying the importance of patient communication of risks for relatives is an essential component of pre- and post-test genetic counseling. Studies suggest that patients undergoing genetic testing recognize their responsibility to share genetic risk with at-risk family members (33,40,41). For example, among 383 women attending a breast cancer genetics clinic in France, where legislation prohibits disclosure of genetic information without consent of the proband under all circumstances, 91.4% said they would inform at least one first-degree relative (41). Additionally, several studies have shown that the majority of patients who undergo *BRCA1/2* testing voluntarily disclose their genetic test results to at-risk family members (42–45), although rates of disclosure vary according to individual patient and relative factors (46,47). Patients share genetic risk information with at-risk female relatives more frequently than at-risk male relatives (42). Additionally, probands communicate genetic risk information to first-degree relatives more frequently than more distant relatives (43–45,48). Several barriers to patient communication with at-risk relatives have been described, including geographic and social distance, disrupted relationships, and perceived relative anxiety, misunderstanding or disinterest in the information (43,44,47–51). Several studies suggest that the responsibility to share genetic information with at-risk relatives can be experienced as a burden for patients who undergo testing, and that sharing information can be difficult (42,48). Although many patients communicate the familial genetic risk to some at-risk family members, 60% of medical geneticists reported experiencing at least one patient's refusal to notify an at-risk relative (36). Thus, the efficiency of the practice of encouraging patients to communicate with at-risk relatives has been questioned. This limited data suggests that many at-risk relatives are not informed of their risk, and after communication, few undergo recommended genetic testing (45). Given concerns about patient's inadequate or ineffectual communication of genetic risk to at-risk relatives, providers of genetic services have considered taking a more active role in communicating genetic risks to relatives. There are advantages and disadvantages to this approach (Table 2). Two recent studies evaluated alternative methods of notifying at-risk relatives of a genetic risk for cancer. The South Australian Familial Cancer Service evaluated the impact of letters mailed from the genetics service to at-risk relatives and found potential benefit to direct notification by the genetics service (52). Additionally, although some at-risk relatives who received letters of notification contacted the service to decline further information, there were no reports from patients or relatives about invasion of privacy. Similarly, Aktan-Collan et al. (53) evaluated direct contact of at-risk family members among hereditary colon cancer kindreds. The majority of patients approved of direct contact and reported high satisfaction with their genetic services. Direct contact of at-risk family members has also been evaluated in other hereditary conditions including familial hypercholesterolemia, cystic fibrosis, Duchenne muscular dystrophy, and alpha-1 anti-trypsin deficiency (54). In several studies, contacted at-risk family members were satisfied with contact by the health care team, did not feel it was improper and indicated a preference for contact by the health care team, rather than their family member (55). These studies suggest a potential for alternative models for informing of at-risk relatives, although further research is necessary to assess the risks and benefits of such an approach before direct contact of at-risk family members by providers can be routinely recommended. Additionally, updates in the legal aspects and expectations of health care professionals will significantly inform such investigations and future policies.

Table 2. Potential Advantages and Disadvantages of Provider Communication of Genetic Risk to At-Risk Relatives

Advantages
Increase uptake of surveillance and preventive health behaviors
Increase accuracy of information conveyed to at-risk relatives
Decrease burden for the patient
Increase fulfillment of provider's obligation to warn at-risk individuals
Disadvantages
Perceived violation of patients' or at-risk relatives' privacy
Perceived violation of patients' or at-risk relatives' autonomy
Perceived pressure or undue influence among relatives
Negative impact on family relationships

COMMUNICATION OF GENETIC RISK TO MINOR OFFSPRING

Although the responsibility of sharing information with at-risk adult relatives is accepted among patients and health care practitioners, there is ongoing debate over the value of sharing genetic risk information with, and offering genetic testing to at-risk minor relatives. Risk-reduction options for mutation carriers (prophylactic surgeries, heightened surveillance, and/or chemoprevention) are generally not recommended until the age of 25 (56,57). Thus, there is no known medical benefit to communicating risk to at-risk minors. Professional societies have recommended against offering *BRCA1/2* testing to children under the age of 18-years old (yo) unless there is an urgent medical indication (58–62). Yet, there remains considerable debate regarding early communication of genetic risk and testing of minors for BRCA1/2 mutations and other adult-onset genetic disorders (63–69). Ethical and clinical arguments have identified potential advantages and disadvantages to early communication of genetic risk to at-risk minor relatives (Table 3), although there is no empiric data to support either early communication of genetic risk to at-risk offspring or withholding such information until adulthood.

Professional recommendations against the genetic testing of minors for cancer syndromes that present in adulthood do not preclude communication of familial risk to children and adolescents. There is evidence that many parents do share their genetic test results and information about familial risk for cancer with minor at-risk children (70–75). This is not surprising given that children (as young as 6 yo) and adolescents in families affected by cancer are informed of their parent's cancer (76–80). Several studies have suggested that adolescents are aware and concerned about their own risk for cancer (70–75, 77–81). Approximately 50% of parents who undergo *BRCA1/2* testing inform at-risk minors of their genetic test result (81–83). Parents have reported disclosure of their *BRCA1/2* mutation to children as young as 7 yo (83) and studies suggest that the majority of late adolescent (14–17 yo) offspring learn of the risk in the family (82,83). Mothers appear more likely than fathers to communicate risk to minor offspring (81,83) and parents of daughters may be more likely to communicate risk to offspring (82). Additionally, there is some evidence that parents with higher baseline distress are more likely to communicate risk to offspring, suggesting that parent communication to offspring may be a parental mechanism for coping with distress (84). Parents report disclosing because they feel responsible for sharing the information, they believe the child had a right to know of the results and they want to increase their child's awareness of the risk in the family to explain the family history and/or their own medical interventions. The most common reason parent's do not communicate risk with offspring is because they feel their offspring are too young for the information (81,83,85).

Table 3. Potential Advantages and Disadvantages of Early Communication of Genetic Risk to Minor Offspring

Advantages
Motivate offspring to adopt preventive or promotive health behaviors
Foster open communication and honesty in the family
Transmit essential medical information
Allow offspring to plan educational, social and family goals
Disadvantages
Increase offspring anxiety or fear about cancer (in self or family members)
Promote perceptions of fatalism and/or risk-taking behaviors
Alter offspring expectations for educational social and familial goals

Few studies have evaluated offspring understanding and psychosocial responses to early communication of familial risk. Parents have reported variable understanding and psychological responses among offspring learning of their *BRCA1/2* mutation (83). Interviews with adult offspring, many of whom learned of their parents *BRCA1/2* mutation during adolescence, suggests that many offspring appear to understand the risk communicated by their parent (78). Similar to parent reports, some offspring reported negative reactions to parental communication of familial risk and identified the need to provide offspring with emotional support, although many were not surprised by the information and did not find it distressing (78,85). Although, there are no specific medical recommendations for preventive behaviors or risk-reduction measures for minors and young adults from *BRCA1/2* families before age 25 yo, many reported changing their health behaviors (i.e., stopping smoking, improving their diet or increasing physical activity) in response to parental communication of the familial risk (78). Nonetheless, further research and direct evaluation among minor offspring is needed to understand the risks and benefits of both early disclosure and nondisclosure of genetic risk. How children, adolescents and young adults interpret and understand the concepts of cancer as a genetic disease and predictive

cancer genetic testing needs to be better understood. The effect on family relationships, emotional health, health-related behaviors, and the desire and uptake for genetic counseling for at-risk offspring are also areas for further investigation. This information is crucial for health care providers involved in caring for families who are at high risk for cancer. It is also essential, considering the unresolved ethical concerns of genetic testing of minors for adult-onset heritable disease. While genetic testing of minors is currently not recommended, interest in the genetic testing of minors among potential consumers has increased in recent years. In a recent study of parents who underwent *BRCA1/2* testing, almost half supported the testing of minor offspring in some or all circumstances (86). Additionally, there is data suggesting that providers of adolescent health care would consider offering *BRCA1/2* testing to minor offspring (87). Thus, further research evaluating the impact of communicating genetic risk to offspring can inform the ongoing debate over when to offer pre-symptomatic testing for hereditary predisposition for adult cancers.

In summary, increased availability and heightened consumer awareness of ''cancer genes'' has increased consumer interest in, and demand for cancer risk assessment, and thus a pressing need for providers to identify effective, efficient methods of communicating complicated genetic information to consumers and their potentially at-risk relatives. Optimizing adherence to recommended risk management strategies, psycho-social well-being and communication to at-risk family members requires not only the effective communication of risk information, but an understanding of the consumers' translation of that information into personalized perceptions of risk of disease and benefits of interventions. Further research evaluating the risks and benefits of telephone and web-based genetic services, of providers taking a more active role in communication of genetic risk to at-risk relatives, and of early communication of genetic risk to minor offspring is needed to inform guidelines regarding effective delivery of genetic services for breast cancer susceptibility.

Acknowledgment

This research study was supported by American Cancer Society, Grant # MRSG-07-014-01-CPPB.

Disclosure

The authors have no conflicts of interest to declare.

REFERENCES

1. American Society of Clinical Oncology policy statement update: genetic testing for cancer susceptibility. *J Clin Oncol* 2003;21:2397–406.

2. Burgess MM. Beyond consent: ethical and social issues in genetic testing. *Nat Rev Genet* 2001;2:147–51.

3. Croyle RT, Lerman C. Risk communication in genetic testing for cancer susceptibility. *J Natl Cancer Inst Monogr* 1999;25:59–66.

4. Rabinowitz B. Breast cancer genetics and psychosocial issues. *Breast J* 1998;4:386–90.

5. Hopwood P. Hereditary breast cancer: psychological aspects of counseling, surveillance and management. *Breast J* 1997;3S:7–14.

6. Bowen DJ, Burke W, McTiernan A, *et al.* Breast cancer risk counseling improves women's functioning. *Patient Educ Couns* 2004;53:79–86.

7. Harris M, Winship I, Spriggs M. Controversies and ethical issues in cancer-genetics clinics. *Lancet Oncol* 2005;6:301–10.

8. Berliner JL, Fay AM. Risk assessment and genetic counseling for hereditary breast and ovarian cancer: recommendations of the National Society of Genetic Counselors. *J Genetic Counsel* 2007;16:241–60.

9. Schwartz GF, Hughes KS, Lynch HT, *et al.* Proceedings of the international consensus conference on breast cancer risk, genetics, & risk management, April, 2007. *Cancer* 2008;113:2627–37.

10. Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. *Ann Intern Med* 2005;143:355–61.

11. Braithwaite D, Emery J, Walter F, *et al.* Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. *Fam Cancer* 2006;5:61–75.

12. Brain K, Gray J, Norman P, *et al.* Randomized trial of a specialist genetic assessment service for familial breast cancer. *J Natl Cancer Inst* 2000;92:1345–51.

13. Calzone KA, Prindiville SA, Jourkiv O, *et al.* Randomized comparison of group versus individual genetic education and counseling for familial breast and/or ovarian cancer. *J Clin Oncol* 2005;23:3455–64.

14. Mikkelsen EM, Sunde L, Johansen C, *et al.* Psychosocial consequences of genetic counseling: a population-based follow-up study. *Breast J* 2009;15:61–8.

15. Edwards A, Gray J, Clarke A, *et al.* Interventions to improve risk communication in clinical genetics: systematic review. *Patient Educ Couns* 2008;71:4–25.

16. Sivell S, Iredale R, Gray J, *et al.* Cancer genetic risk assessment for individuals at risk of familial breast cancer. *Cochrane Database Syst Rev* 2007:CD003721.

17. Keating NL, Stoeckert KA, Regan MM, *et al.* Physicians' experiences with BRCA1/2 testing in community settings. *J Clin Oncol* 2008;26:5789–96.

18. Chen WY, Garber JE, Higham S, *et al.* BRCA1/2 genetic testing in the community setting. *J Clin Oncol* 2002;20:4485–92.

19. Bradbury AR, Patrick-Miller L, Fetzer D, *et al. Telephone Disclosure of BRCA1/2 Test Results: A Survey of Genetic Counselors.* [abstract]. San Antonio, TX: The San Antonio Breast Cancer Symposium, 2008.

20. Wang VO. Commentary: what is and is not telephone counseling? *J Genetic Counsel* 2000;9:73–82.

21. Coelho JJ, Arnold A, Nayler J, *et al.* An assessment of the efficacy of cancer genetic counselling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations. *Eur J Cancer* 2005;41:2257–61.

22. Helmes AW, Culver JO, Bowen DJ. Results of a randomized study of telephone versus in-person breast cancer risk counseling. *Patient Educ Couns* 2006;64:96–103.

23. Gattas MR, MacMillan JC, Meinecke I, *et al.* Telemedicine and clinical genetics: establishing a successful service. *J Telemed Telecare* 2001;7(Suppl. 2):68–70.

24. Stalker HJ, Wilson R, McCune H, *et al.* Telegenetic medicine: improved access to services in an underserved area. *J Telemed Telecare* 2006;12:182–5.

25. Ormond KE, Haun J, Cook L, *et al.* Recommendations for telephone counseling. *J Genetic Counsel* 2000;9:63–71.

26. Sangha KK, Dircks A, Langlois S. Assessment of the effectiveness of genetic counseling by telephone compared to a clinic visit. *J Genetic Counsel* 2003;12:171–84.

27. Patrick-Miller L, Fetzer D, Schmidheiser H, *et al. Telephone Disclosure of BRCA1/2 Test Results? Opinions of Recipients of BRCA1/2 Testing.* [abstract]. San Antonio, TX: San Antonio Breast Cancer Symposium, 2008.

28. Klemp JR, O'Dea A, Chamberlain C, *et al.* Patient satisfaction of BRCA1/2 genetic testing by women at high risk for breast cancer participating in a prevention trial. *Fam Cancer* 2005;4:279–84.

29. Jenkins J, Calzone KA, Dimond E, *et al.* Randomized comparison of phone versus in-person BRCA1/2 predisposition genetic test result disclosure counseling. *Genet Med* 2007;9:487–95.

30. Peshkin BN, Demarco TA, Graves KD, *et al.* Telephone genetic counseling for high-risk women undergoing BRCA1 and BRCA2 testing: rationale and development of a randomized controlled trial. *Genet Test* 2008;12:37–52.

31. Godard B, Hurlimann T, Letendre M, *et al.* Guidelines for disclosing genetic information to family members: from development to use. *Fam Cancer* 2006;5:103–16.

32. Merz JF, Cho MK, Sankar P. Familial disclosure in defiance of nonconsent. *Am J Hum Genet* 1998;63:898–900.

33. Lehmann LS, Weeks JC, Klar N, *et al.* Disclosure of familial genetic information: perceptions of the duty to inform. *Am J Med* 2000;109:705–11.

34. Offit K, Groeger E, Turner S, *et al.* The ''duty to warn'' a patient's family members about hereditary disease risks. *JAMA* 2004;292:1469–73.

35. Dugan RB, Wiesner GL, Juengst ET, *et al.* Duty to warn at-risk relatives for genetic disease: genetic counselors' clinical experience. *Am J Med Genet C Semin Med Genet* 2003;119:27–34.

36. Falk MJ, Dugan RB, O'Riordan MA, *et al.* Medical geneticists' duty to warn at-risk relatives for genetic disease. *Am J Med Genet A* 2003;120A:374–80.

37. Tarasoff v. et al., Regents of the University of California, et al. (1976): Reargued 17 Cal3d 425.551, p2 d334, 161 (Cal Reptr 1976), 33.

38. Pate v. Threlkel, 661 So. 2d.278, (Fla. 1995).

39. Safer v. Estate of Pack, 677 A.2d (N.J. Super. Ct. App' Div. 1996).

40. Hallowell N, Ardern-Jones A, Eeles R, *et al.* Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: patterns, priorities and problems. *Clin Genet* 2005;67:492–502.

41. Julian-Reynier C, Eisinger F, Chabal F, *et al.* Disclosure to the family of breast/ovarian cancer genetic test results: patient's willingness and associated factors. *Am J Med Genet* 2000;94:13–8.

42. Wagner Costalas J, Itzen M, Malick J, *et al.* Communication of BRCA1 and BRCA2 results to at-risk relatives: a cancer risk assessment program's experience. *Am J Med Genet C Semin Med Genet* 2003;119:11–8.

43. McGivern B, Everett J, Yager GG, *et al.* Family communication about positive BRCA1 and BRCA2 genetic test results. *Genet Med* 2004;6:503–9.

44. Stoffel EM, Ford B, Mercado RC, *et al.* Sharing genetic test results in Lynch syndrome: communication with close and distant relatives. *Clin Gastroenterol Hepatol* 2008;6:333–8.

45. Finlay E, Stopfer JE, Burlingame E, *et al.* Factors determining dissemination of results and uptake of genetic testing in families with known BRCA1/2 mutations. *Genet Test* 2008; 12:81–91.

46. Smith KR, Zick CD, Mayer RN, *et al.* Voluntary disclosure of BRCA1 mutation test results. *Genet Test* 2002;6:89–92.

47. Ormondroyd E, Moynihan C, Ardern-Jones A, *et al.* Communicating genetics research results to families: problems arising when the patient participant is deceased. *Psychooncology* 2008;17:804–11.

48. Claes E, Evers-Kiebooms G, Boogaerts A, *et al.* Communication with close and distant relatives in the context of genetic testing for hereditary breast and ovarian cancer in cancer patients. *Am J Med Genet A* 2003;116A:11–9.

49. Hughes C, Lerman C, Schwartz M, *et al.* All in the family: evaluation of the process and content of sisters' communication about BRCA1 and BRCA2 genetic test results. *Am J Med Genet* 2002;107:143–50.

50. Barsevick AM, Montgomery SV, Ruth K, *et al.* Intention to communicate BRCA1/BRCA2 genetic test results to the family. *J Fam Psychol* 2008;22:303–12.

51. Kenen R, Arden-Jones A, Eeles R. We are talking, but are they listening? Communication patterns in families with a history of breast/ovarian cancer (HBOC) *Psychooncology* 2004;13:335–45.

52. Suthers GK, Armstrong J, McCormack J, *et al.* Letting the family know: balancing ethics and effectiveness when notifying relatives about genetic testing for a familial disorder. *J Med Genet* 2006;43:665–70.

53. Aktan-Collan K, Haukkala A, Pylvanainen K, *et al.* Direct contact in inviting high-risk members of hereditary colon cancer families to genetic counselling and DNA testing. *J Med Genet* 2007;44:732–8.

54. de Wert G. Cascade screening: whose information is it anyway? *Eur J Hum Genet* 2005;13:397–8.

55. Newson AJ, Humphries SE. Cascade testing in familial hypercholesterolaemia: how should family members be contacted? *Eur J Hum Genet* 2005;13:401–8.

56. Daly MB, Axilbund JE, Bryant E, *et al. The National Comprehensive Cancer Network Clinical Practive Guidelines in Oncology, Genetic/Familial High-Risk Assessment: Breast and Ovarian* (ed v.1.2007), . Fort Washington: National Comprehensive Cancer Network, 2007

57. Burke W, Daly M, Garber J, *et al.* Recommendations for follow-up care of individuals with an inherited predisposition to cancer. II. BRCA1 and BRCA2. Cancer Genetics Studies Consortium. *JAMA* 1997;277:997–1003.

58. Borry P, Stultiens L, Nys H, *et al.* Presymptomatic and predictive genetic testing in minors: a systematic review of guidelines and position papers. *Clin Genet* 2006;70:374–81.

59. ASHG/ACMG. Points to consider: ethical, legal, and psychosocial implications of genetic testing in children and adolescents. American Society of Human Genetics Board of Directors, American College of Medical Genetics Board of Directors. *Am J Hum Genet* 1995;57:1233–41.

60. The Working Party of the Clinical Genetics Society (UK). The genetic testing of children. *J Med Genet* 1994;31:785–97.

61. ASCO. American Society of Clinical Oncology policy statement update: genetic testing for cancer susceptibility. *J Clin Oncol* 2003;21:2397–406.

62. Kodish ED. Testing children for cancer genes: the rule of earliest onset. *J Pediatr* 1999;135:390–5.

63. Borry P, Goffin T, Nys H, *et al.* Predictive genetic testing in minors for adult-onset genetic diseases. *Mt Sinai J Med* 2008;75:287–96.

64. Cohen CB. Wrestling with the future: should we test children for adult-onset genetic conditions? *Kennedy Inst Ethics J* 1998;8:111–30.

65. Rhodes R. Why test children for adult-onset genetic diseases? *Mt Sinai J Med* 2006;73:609–16.

66. Elger BS, Harding TW. Testing adolescents for a hereditary breast cancer gene (BRCA1): respecting their autonomy is in their best interest. *Arch Pediatr Adolesc Med* 2000;154:113–9.

67. Robertson S, Savulescu J. Is there a case in favour of predictive genetic testing in young children? *Bioethics* 2001;15:26–49.

68. Pelias MK. Genetic testing of children for adult-onset diseases: is testing in the child's best interests? *Mt Sinai J Med* 2006;73:605–8.

69. Malpas PJ. Predictive genetic testing of children for adult-onset diseases and psychological harm. *J Med Ethics* 2008;34:275–8.

70. Forrest G, Plumb C, Ziebland S, *et al.* Breast cancer in the family–children's perceptions of their mother's cancer and its initial treatment: qualitative study. *BMJ* 2006;332:998–1003.

71. Zahlis EH. The child's worries about the mother's breast cancer: sources of distress in school-age children. *Oncol Nurs Forum* 2001;28:1019–25.

72. Compas BE, Worsham NL, Epping-Jordan JE, *et al.* When mom or dad has cancer: markers of psychological distress in cancer patients, spouses, and children. *Health Psychol* 1994;13:507–15.

73. Fitch MI, Abramson T. Information needs of adolescents when a mother is diagnosed with breast cancer. *Can Oncol Nurs J* 2007;17:16–25.

74. Hoke LA. Psychosocial adjustment in children of mothers with breast cancer. *Psychooncology* 2001;10:361–9.

75. Kristjanson LJ, Chalmers KI, Woodgate R. Information and support needs of adolescent children of women with breast cancer. *Oncol Nurs Forum* 2004;31:111–9.

76. Tercyak KP, Peshkin BN, Streisand R, *et al.* Psychological issues among children of hereditary breast cancer gene (BRCA1/2) testing participants. *Psychooncology* 2001;10:336–46.

77. Geller G, Tambor ES, Bernhardt BA, *et al.* Mothers and daughters from breast cancer families: a qualitative study of their perceptions of risks and benefits associated with minor's participation in genetic susceptibility research. *J Am Med Womens Assoc* 2000;55:280–4. 293

78. Bradbury AR, Patrick-Miller L, Pawlowski K, *et al.* Learning of your parent's BRCA mutation during adolescence or early adulthood: a study of offspring experiences. *Psychooncology* 2009;18:200–8.

79. Weiss M, Griggs J, Norton L, *et al. Breast Cancer Fear in Girls: A Major "Side Effect" of Breast Cancer in Loved Ones and a Backlash of Ubiquitous Media Coverage*. San Antonio, TX: The San Antonio Breast Cancer Symposium, 2008.

80. Silk KJ, Bigbsy E, Volkman J, *et al.* Formative research on adolescent and adult perceptions of risk factors for breast cancer. *Soc Sci Med* 2006;63:3124–36.

81. Tercyak KP, Hughes C, Main D, *et al.* Parental communication of BRCA1/2 genetic test results to children. *Patient Educ Couns* 2001;42:213–24.

82. Patenaude AF, Dorval M, DiGianni LS, *et al.* Sharing BRCA1/2 test results with first-degree relatives: factors predicting who women tell. *J Clin Oncol* 2006;24:700–6.

83. Bradbury AR, Dignam JJ, Ibe CN, *et al.* How often do BRCA mutation carriers tell their young children of the family's risk for cancer? A study of parental disclosure of BRCA mutations to minors and young adults *J Clin Oncol* 2007;25:3705–11.

84. Tercyak KP, Peshkin BN, DeMarco TA, *et al.* Parent-child factors and their effect on communicating BRCA1/2 test results to children. *Patient Educ Couns* 2002;47:145–53.

85. Clarke S, Butler K, Esplen MJ. The phases of disclosing BRCA1/2 genetic information to offspring. *Psychooncology* 2008;17:797–803.

86. Bradbury AR, Patrick-Miller L, Pawlowski K, *et al.* Should genetic testing for BRCA1/2 be permitted for minors? Opinions of BRCA mutation carriers and their adult offspring *Am J Med Genet C Semin Med Genet* 2008;148C:70–7.

87. O'Neill SC, Peshkin BN, Luta G, *et al.* Primary care providers' willingness to recommend BRCA1/2 testing to adolescents. *Fam Cancer*, 2009., doi: 10.1007/s10689-009-9243-y