Concerns of women presenting to a comprehensive cancer centre for genetic cancer risk assessment

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About 5–10% of breast and ovarian cancers are the result of an autosomal dominant inherited predisposition, with a significant portion resulting from a germline mutation in the highly penetrant *BRCA1* or *BRCA2* genes.¹ The risk for breast cancer in women who carry a *BRCA* mutation is estimated to be 33–50% by the age of 50 and 56–85% by the age of 70,^{1–4} and the risk of a second breast cancer may be as high as 60% over a woman's lifetime. The risk of ovarian cancer ranges from about 10–50%. Women are increasingly presenting for genetic cancer risk assessment (GCRA) services, wherein genetic testing and empirical data may be used to predict breast and ovarian cancer risk. Risk management options ranging from close surveillance to chemoprevention to prophylactic surgery are discussed as part of the GCRA consultation. While there is clearly a potential to benefit carefully selected and counselled subjects and family members who choose to undergo predisposition genetic testing,^{5,6} numerous barriers exist to the appropriate application of this emerging technology.^{7,8} Attention to the psychological implications of hereditary cancer including passing on a disease associated gene to one's children (transmission guilt) or alterations in family relationships are inherent in the counselling process. It is essential to understand the needs, beliefs, and values of women who seek GCRA services.⁹ The purpose of this pilot study was to ascertain the motivations and concerns of women presenting to a comprehensive cancer centre for GCRA in order to understand their needs better. The study findings provided valuable insights into women's concerns and served as the basis for an ongoing comprehensive evaluation of needs in a larger cohort.

METHODS

Eligibility

The study was approved by both the City of Hope's (COH) clinical protocol review and monitoring committee and institutional review board. Eligibility included all adult women with a personal or family history of breast or ovarian cancer, able to give informed consent, scheduled for an initial GCRA appointment at the City of Hope (COH) National Medical Center, *Cancer Screening & Prevention Program* (CSPP). Women who had previously undergone cancer risk counselling were ineligible. Study participation consisted of answering a one time pre-GCRA questionnaire.

Recruitment/sampling

A detailed health and family history questionnaire is sent to anyone who has an appointment in the CSPP clinic before their initial clinic visit. Consecutive women eligible for this study were also sent an invitation letter describing the study, study questionnaire, consent, and a self-addressed stamped envelope to return the study materials to the investigator. Women who returned the completed questionnaire and consent form before the initial GCRA appointment were enrolled and assigned a unique study ID number. Recruitment

began in June 1998 and continued until the sample size (n=50) was met in July 1999. One hundred and twenty study packets were mailed to obtain the 50 participants. Forty-six participants were referred by a physician and four were self-referred. Participants consisted of 27 women treated for breast or ovarian cancer and 23 unaffected women who had a family history of these cancers.

Survey instruments

The study used a one time exploratory methodology to collect quantitative and qualitative data. Age, personal and family cancer history with ages at diagnosis, personal health history including risk factors related to breast and ovarian cancer, and ethnicity was collected on all participants. The study questions were revised before study implementation based on pilot testing for readability, clarity, and time for completion (average of 17 minutes) by three non-health care professionals, a nurse educator, and a nurse cancer risk counsellor practising in the mid-west. The study questions were designed to ascertain perceptions about: (1) magnitude of their own personal cancer risk; (2) cancer risk in general; (3) concerns about developing cancer; (4) acceptable options for cancer prevention and risk management; (5) issues about genetic testing for cancer risk; (6) communicating risk to other family members, and (7) how women learn about cancer risk. Two versions of the questionnaire were used, one for affected women and the other for unaffected women. Space was provided throughout the questionnaire for open ended comments. Subjects were asked to rate on a scale of 0 = "no risk" to 100% = "inevitable" what they believed was their own lifetime and 10 year risk for developing breast cancer. Beliefs about general population risk for breast, ovarian, uterine, and colon cancer, the age at which a woman was at greatest risk for breast cancer, and the percentage of women with breast cancer who had a family history of the disease were also ascertained. In evaluating cancer concerns, a checklist of "never/rarely," "sometimes," "often", or "all the time" was used to assess the frequency of concerning thoughts about developing cancer and how often these thoughts interfered with one's life/daily activities. For risk management, women were asked to check a response of "yes," "no," "unsure", or "not applicable" on nine questions regarding what they might be willing to do if determined by a genetic test to be at greater than 50% risk for breast cancer. Women were also asked to rank, in order of first, second, third, "would not choose", or "not applicable" their preferences for managing breast cancer risk. Risk management choices included close surveillance, participating in a research study of a medication to reduce risk, and prophylactic surgery. Similar

Abbreviations: GCRA, genetic cancer risk assessment; COH, City of Hope; CSPP, *Cancer Screening & Prevention Program*; FDR, first degree relative; SDR, second degree relative; OC, oral contraceptives

Table 1 Subject characteristics

	Affected	Unaffected
Total No	27	23
Breast ca	23	
Bilateral breast ca	2	
DCIS	2	
Ovarian ca	1	
Breast and ovarian ca	1	
Average age at study entry X, SD (range)	45, 14 (24–77)	41, 10 (26–65)
Age at cancer diagnosis	40, 10 (22–58)	
Oral contraceptive use	7/27 (26%)	4/18 (17%)
Hormone replacement therapy use	1	1
≥ 1 FDR with breast or ovarian ca	10	23
Ethnicity	Affected and unaffected combined	
White	40	
Mixed heritage	6	
Hispanic	2	
African American	1	
Asian	1	

questions were used for risk management of ovarian cancer risk, with the additional choice of using oral contraceptives for potential risk management. Regarding genetic testing, women were asked to circle either “not important,” “somewhat important,” “very important,” or “not applicable” for eleven factors on deciding whether or not to undergo genetic testing for breast cancer risk. Questions assessing communication of risk included a checklist of first, second, and third degree relatives and a “spouse/partner” category for delineating persons women had discussed cancer risk with, and a list of seven potential barriers to discussing risk. Another question surveyed whether participants thought that there was a duty to inform relatives about hereditary cancer risk if it existed and, if so, who (clinicians *v* themselves) should do the informing and how (in person, by phone, or by mail). Subjects were also asked to note any relatives diagnosed with cancer, the type of cancer, and the age at onset. Finally, four questions asked how women learn information about cancer, if they found this information useful, and the effect, if any, on their level of anxiety.

Open ended questions interspersed throughout the questionnaire asked each subject to describe what factors she believed influenced her own and any woman's risk for cancer, how thoughts about developing cancer affected her, additional ways she might use to manage personal breast and ovarian cancer risk, why she would want or not want to have genetic testing for breast/ovarian cancer associated genes, whether she thought she was genetically predisposed to breast/ovarian cancer and why, and if she had any additional reasons than those listed which were important to her in deciding to have or not have testing.

Analysis

Quantitative data are reported as frequency counts, percentages, standard deviations, and means for the two study populations. Data from each of the open ended questions were summarised and responses aggregated on each question. Final summary of the data was organised to represent the content from each category of the instrument.

Subject characteristics

Participants consisted of 27 affected women (mean age 45) and 23 unaffected women (mean age 41) with a family history of breast or ovarian cancer. The mean time from initial cancer diagnosis to study entry was just under 5 years. The majority of participants were white. Eleven (22%) listed their ethnic background as at least partly of a minority group (table 1).

None of the unaffected women had ever had a breast biopsy or other breast surgery. Thirty-seven percent of the affected cohort (10/27) had a first degree relative (FDR) with breast or ovarian cancer: two participants (one with ovarian cancer) had a FDR with ovarian cancer, one had two FDRs with breast cancer, and seven had one FDR with the disease. An extended family history (SDR or greater) of breast and ovarian cancers in the paternal lineage was present for one subject in the latter group. Two affected women had only a third degree relative with breast cancer. Of the unaffected women, one had a FDR with both breast and ovarian cancer, two had a FDR with ovarian cancer only, and 17 had at least one FDR with breast cancer (including two cases of bilateral disease). One woman had four FDRs with breast cancer and a SDR with ovarian cancer and two women had two FDRs with breast cancer (table 1) Two unaffected women without affected FDRs had a more distant family history of breast and ovarian cancer. One unaffected woman who had a first degree relative with ovarian cancer developed ovarian cancer after study completion. Most subjects also had a family history of other (not breast or ovary) cancers.

RESULTS

Risk perception

The mean perception of personal breast cancer risk for unaffected women was 59% (range 5–100%) compared to the mean lifetime breast cancer risk of 17% (range 4–35%) and 22% (range 10–34%) predicted by the Gail model and Claus tables, respectively.^{10–12} Intra-personal comparisons were not done. Affected women were asked to recall what they thought their chance of having breast cancer was before disease onset. Responders (n=19) noted a range of 0–100% with a mean of 31% (SD 34), slightly more than half the risk reported by the unaffected group, despite a near similar risk range of 5–100%. The lowest risk was reported by the youngest women and, unexpectedly, by the women who had undergone bilateral mastectomy. Many of the women who perceived themselves as at risk (both cohorts) thought that their chance of having breast cancer was confined to the next 10 years. The 10 year breast cancer risk estimates ranged from 0–75% (mean 33%, SD 24) for affected responders (n=17) and 0–100% (mean=56%, SD 32) for unaffected responders (n=21). Interestingly, subjects were less likely to perceive themselves to be at risk for breast, ovarian, uterine, or colon cancer if they had already had cancer. Both the affected (n=22) and unaffected (n=18) groups overestimated the general population risk for

Table 2 Breast cancer risk reduction options*

Options	A	U
Breast self-exam monthly	100% (25/25)	96% (22/23)
Clinical breast exam more frequently	96% (22/23)	100% (25/25)
Mammogram annually, beginning in their 30s	96% (24/25)	95% (21/22)
Self-pay for office visits or mammogram	73% (19/26)	74% (17/23)
Use of hormonal medication	86% (18/21)	78% (14/18)
Prophylactic mastectomy	48% (13/27)	39% (9/23)

*Women were asked what they would be willing to do to reduce their risk for breast cancer (A = affected, U = unaffected).

Table 3 Ranking ovarian cancer risk reduction options*

Options	1st choice		Would not choose as option	
	A	U	A	U
Close surveillance	50% (12/24)	52% (11/21)	0%	0%
Oral contraceptive	6% (1/18)	10% (2/20)	28% (5/18)	15% (3/20)
Chemoprevention	20% (4/20)	15% (3/20)	15% (3/20)	20% (4/20)
Prophylactic oophorectomy	48% (11/23)	25% (5/20)	1% (1/23)	0%

*Women were asked to rank risk reduction options in order of preference (1st, 2nd, 3rd choice, or "would not choose as option").
A = affected, U = unaffected.

breast cancer (mean 27% and 21%, respectively, NS) and the general population risk for ovarian cancer (mean 19% and 14%, respectively, NS). Similarly, both groups thought that the general population had nearly the same risk for uterine or colon cancer and greatly overestimated risks for these cancers.

Cancer concerns

When asked "How often do thoughts about cancer concern you" about half in each group reported "sometimes". Only 15% of the affected women reported "often" or "all the time" in comparison to 19% of unaffected responders (n=21). While all of the unaffected responders (n=21) had at least occasional thoughts concerning cancer, 7% (2/27) of all affected women rarely or never had thoughts about cancer recurring. Overall, thoughts about cancer rarely or never interfered with subjects' lives or daily activities for 67% of all affected women (18/27) and 64% of unaffected responders (n=22); however, 26% of affected women and 36% of unaffected responders said that these thoughts disrupted their lives sometimes or often. One affected responder worried about cancer recurrence "all the time".

Breast cancer risk management

Each subject was asked about measures they would be willing to take to manage breast or ovarian cancer risk if genetic testing determined that they were at greater than 50% risk for cancer. Nearly all participants would be willing to perform monthly breast self-examinations, have more frequent clinical breast examinations, and have annual mammograms beginning in their 30s. About 75% of both cohorts would be willing to pay out of pocket for an office visit or mammograms not covered by insurance. Eighty-six percent of the affected women and 77% of the unaffected women would be in favour of taking a hormonal medication that had no serious side effects, to reduce breast cancer risk, but were much less likely to do so if the medication acted as a contraceptive or induced menopause (if applicable). Not surprisingly, more affected (48%) than unaffected women (39%) would undergo bilateral prophylactic mastectomies to reduce risk; however, 30% of all subjects would not choose this strategy at all (table 2).

Ovarian cancer risk management

Women were asked to rank choices for managing ovarian cancer risk. Similar to breast cancer risk management options,

close surveillance was the first choice for reducing risk of ovarian cancer for both groups despite being told that the reliability of surveillance was not proven. Subjects were told that oral contraceptives (OC) could lower the odds of developing ovarian cancer by nearly a half and that several years' use could slightly increase the risk of breast cancer. Twenty-six percent (7/27) of affected responders had previously used oral contraceptives as did 17% (4/18) of unaffected responders. Nevertheless, few responders in either group were willing to use OC, or another medication in a research study, to decrease their chances for the disease. Subjects were told that removal of the ovaries was thought to reduce ovarian cancer risk by about 90%. Forty-eight percent (11/23) of affected responders and 25% (5/20) of unaffected responders would choose this surgery as a first choice to reduce ovarian cancer risk (table 3).

Genetic testing issues

Women in both groups thought that genetic testing for hereditary cancer risk was important in making health care decisions, planning for the future, and knowing if their children could be at risk, and not important for deciding about child bearing or marriage. We found that 50% of affected responders (n=26) were very concerned about possible insurance problems as a result of genetic testing, whereas all unaffected responders (n=19) were much less concerned about this, possibly reflecting insurance burdens already experienced by the affected women. Few study participants thought that the cost of testing was an important issue in the decision to undergo genetic testing, though no information about actual test cost was provided. Eighty-two percent (14/17) of affected responders thought they carried an abnormal *BRCA* gene, as did 67% (12/18) of unaffected responders. We estimated a 15% mean probability of mutation for the affected responders and a 13% mean probability for the unaffected responders.³ For reasons unknown and unexpected, 10 affected and five unaffected women did not answer this question.

Communicating risk

Most women thought that if they were found to have a hereditary predisposition to cancer there was a duty to inform relatives about this and that they, as opposed to health care providers, should be the ones to inform relatives of this risk.

Table 4 Ranking breast cancer risk reduction options*

Options	1st choice		Would not choose as option	
	A	U	A	U
Close surveillance	65% (17/26)	70% (14/20)	0%	0%
Chemoprevention	38% (10/26)	21% (4/19)	8% (2/26)	5% (1/19)
Prophylactic mastectomy	12% (3/25)	11% (2/19)	32% (8/25)	26% (5/19)

*Women were asked to rank risk reduction options in order of preference (1st, 2nd, 3rd choice, or "would not choose as option").

A = affected, U = unaffected.

Affected women were more likely to talk about cancer risk with their spouses/partners than unaffected women. Both cohorts reported that upsetting relatives or recalling painful memories did not prevent them from discussing cancer risk with their family members.

Sources of information

While women used the Internet to obtain information regarding cancer, they viewed information from physicians and magazines, newspapers, or books as more helpful. The information they obtained had little or no effect on the anxiety level of affected responders (n=25) but the unaffected responders (n=20) were nearly equally divided on whether this information raised or lowered their anxiety about cancer or had no effect at all.

DISCUSSION

This pilot study sought to determine the motivations and concerns of women presenting to a comprehensive cancer centre for genetic cancer risk assessment (GCRA), counselling, and testing. The mean age of the unaffected participants (41) is close to the mean age of cancer diagnoses (40) in their relatives and slightly younger than the mean age of the affected cohort (45). For unaffected women, being close to the age of disease onset in a family member may be a milestone accentuating cancer concerns and prompting presentation for GCRA services.

As in previous studies, we found that both unaffected women with a family history of breast or ovarian cancer and women affected with these cancers greatly overestimate their own lifetime, 10 year, and general population risk for breast cancer.¹³⁻¹⁶ Despite similar family histories, perception of personal breast cancer risk was nearly twice as high (59%) for the unaffected women as compared to perceived risk before diagnosis for the affected women (31%). For the latter group, it could be that recollection of perceived risk before diagnosis is inaccurate. Alternatively, similarly to findings of Drossaert *et al.*,¹⁷ the women may have been unaware of the impact of their family history on their own cancer risk. Regarding breast cancer risk in the next 10 years, in our study unaffected women reported an average risk of 56% v 33% for affected women, perhaps reflecting a lesser sense of vulnerability for women who already had been treated for the disease. A factor women often cite as contributing to the likelihood of having breast cancer is the use of oral contraceptives or hormone replacement therapy. In this study only a small proportion of both cohorts had a previous use of either medication, so this would not be expected to account for most participants' risk overestimation. Of note, although both groups overestimated risk for several other common cancers, the affected women thought that their risk for these cancers was lower.

In our study, cancer concerns occurred more often among unaffected women than affected women. Correspondingly, more unaffected than affected women reported having disruptive thoughts about cancer at least occasionally. Cancer concerns, therefore, appear to be more disconcerting for women who have never had the disease. In contrast, Watson *et*

*al*¹⁸ found that 28% of unaffected women with a positive family history in a London cohort had cancer worries "frequently" or "constantly".¹⁸

About three-quarters of all the women reported that they were willing to pay out of pocket if necessary for a clinician visit or mammogram and slightly more were willing to take a risk reduction medication with no serious side effects as long as it did not act as a contraceptive or induce menopause. It had not been anticipated that the women would not want to lose fertility given that the average age of both cohorts was over 40, an age at which the majority might be expected to have completed childbearing. Although more affected than unaffected women would have prophylactic breast removal, a third of all women would not (women were told that this surgery was not proven to prevent breast cancer). For both groups, closer follow up was the first choice for risk management. Many affected women would choose to undergo oophorectomy to reduce ovarian cancer risk whereas the unaffected women would not. Surprisingly, most women were unwilling to use oral contraceptives or another medication to lower ovarian cancer risk (tables 3 and 4).

Not surprisingly, more affected women thought that they carried a genetic predisposition to breast-ovarian cancer than unaffected women. Both groups thought that they should inform their family members about a hereditary cancer risk and many of the women had discussed cancer risk with at least one family member.

Consistent with previous studies, the most reported reasons for desiring genetic testing were to make health care decisions to reduce risk, to plan for the future, and to know if their children could be at risk.¹⁹⁻²⁰ However, we found that reproductive decision making was not considered important regardless of the testing outcome. Potential health care or employment discrimination was a greater concern for affected than unaffected women. Perhaps the women who had experienced cancer had more intense interaction with their health care insurers, fear of job loss because of treatment related absence, and frank contemplation of mortality and reassessment of insurance coverage. Although we found that the cost of testing was not an important factor in deciding to have or not have genetic testing, it is possible that unawareness of the cost and high SES of subjects biased their response.

This study has both similarities and differences with findings from previous studies. It should be noted that most previous studies offered confidential free counselling and genetic testing as part of a grant subsidised study. Our 50 subjects were primarily white women referred by their physicians to an urban comprehensive cancer centre for GCRA in a regular clinical setting of fee for service health care. They may not be representative of lower socioeconomic groups or other ethnic populations. The small sample size also limits generalisation of study data. To help address these limitations we have initiated a study with a much larger sample size, more geographical diversity, and measurement at multiple time-points for women seeking GCRA at COH and two of our satellite clinics.

Findings from our pilot study indicate that providing information related to individual cancer risk, risk management

strategies, genetic testing, and risk to others in the family is important in meeting the needs of women presenting for GCRA. Further research is continuing to confirm and expand upon these observations. Health care clinicians should be aware of the beliefs, values, and concerns of women undergoing GCRA and be prepared to address these issues.

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REFERENCES

- Ford D**, Easton DF, Stratton M, Narod S, Goldgar D, Devilee P, Bishop DT, Weber B, Lenoir G, Chang-Claude J, Sobol H, Teare MD, Struwing J, Arason A, Scherneck S, Peto J, Rebbeck TR, Tonin P, Neuhausen S, Barkardottir R, Eyfjord J, Lynch H, Ponder BAJ, Gayther SA, Birch JM, Lindblom BA, Stoppa-Lyonnet D, Bignon Y, Borg A, Hamann U, Hattes N, Scott RJ, Maugard CM, Vasen H, Seitz S, Cannon-Albright LA, Schofield A, Zelada-Hedman M. Genetic heterogeneity and penetrance analysis of the *BRCA1* and *BRCA2* genes in breast cancer families. *Am J Hum Genet* 1998;**62**:676-89.
- FitzGerald MG**, MacDonald DJ, Krainer M, Hoover I, O'Neil E, Unsal H, Silva-Arrieto S, Finkelstein DM, Beer-Romero P, Englert C, Sgroi DC, Smith BL, Younger JW, Garber JE, Duda RB, Mayzel KA, Isselbacher KJ, Friend SH, Haber DA. Germ-line *BRCA1* mutations in Jewish and non-Jewish women with early-onset breast cancer. *N Engl J Med* 1996;**334**:143-9.
- Couch F**, DeShano ML, Blackwood A, Calzone K, Stopfer J, Campeau L, Ganguly A, Rebbeck T, Weber BL. *BRCA1* mutations in women attending clinics that evaluate the risk of breast cancer. *N Engl J Med* 1997;**336**:1409-15.
- Struwing JP**, Hartge P, Wacholder S, Baker SM, Berlin M, McAdams M, Timmerman MM, Brody LC, Tucker MA. The risk of cancer associated with specific mutations of *BRCA1* and *BRCA2* among Ashkenazi Jews. *N Engl J Med* 1997;**336**:1401-8.
- Hoskins KF**, Stopfer JE, Calzone KA, Merajver SD, Rebbeck TR, Garber JE, Weber BL. Assessment and counseling for women with a family history of breast cancer - a guide for clinicians. *JAMA* 1995;**273**:577-85.
- Weitzel JN**. Genetic cancer risk assessment: putting it all together. *Cancer* 1999;**86**:2483-92.
- Alexandre LM**. Genetic testing for cancer susceptibility: what your institution needs to know. *Oncology Issues* 1997;**18**:20.
- MacDonald DJ**. Ethical, legal, and social issues related to predisposition testing for breast cancer risk: what nurses need to know. *Qual Life* 1997;**6**:8-14.
- Lerman C**, Lustbader E, Rimer B, Daly M, Miller S, Sands C, Balshem A. Effects of individualized breast cancer risk counseling: a randomized trial. *J Natl Cancer Inst* 1995;**87**:286-92.
- Gail MH**, Brinton LA, Byar DP, Corle DK, Green SB, Schairer C, Mulvihill JJ. Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. *J Natl Cancer Inst* 1989;**81**:1879-86.
- Claus EB**, Risch N, Thompson WD. Autosomal dominant inheritance of early-onset breast cancer: implications for risk prediction. *Cancer* 1994;**73**:643-51.
- Claus EB**, Risch N, Thompson WD. The calculation of breast cancer risk for women with a first degree family history of ovarian cancer. *Breast Cancer Res Treatment* 1993;**28**:115-20.
- Smith BL**, Gadd MA, Lawler C, MacDonald D, Grudberg SC, Chi FS, Carlson K, Comegno A, Souba WW. Perception of breast cancer risk among women in breast center and primary care settings: correlation with age and family history of breast cancer. *Surgery* 1996;**120**:297-302.
- Bluman LG**, Rimer BK, Berry DA, Borstelmann N, Iglehart JD, Regan K, Schildkraut J, Winer EP. Attitudes, knowledge, and risk perceptions of women with breast and/or ovarian cancer considering testing for *BRCA1* and *BRCA2*. *J Clin Oncol* 1999;**17**:1040-6.
- Duffy SJ**, Bowen DJ, McTiernan A, Sporleder J, Burke W. Attitudes and interest in genetic testing for breast and ovarian cancer susceptibility in diverse groups of women in western Washington. *Cancer Epidemiology Biomarkers Prev* 1999;**8**:369-75.
- Cull A**, Fry A, Rush R, Steel C. Cancer risk perceptions and distress among women attending a familial ovarian cancer clinic. *Br J Cancer* 2001;**84**:594-9.
- Drossaert C**, Boer H, Seydel E. Perceived risk, anxiety, mammogram uptake, and breast self-examination of women with a family history of breast cancer: the role of knowing to be at increased risk. *Cancer Detect Prev* 1996;**20**:76-85.
- Watson M**, Lloyd S, Davidson J, Meyer L, Eeles R, Ebs S, Murday V. The impact of genetic counselling on risk perception and mental health in women with a family history of breast cancer. *Br J Cancer* 1999;**79**:868-74.
- Lerman C**, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. *J Clin Oncol* 1994;**12**:843-50.
- Hofferbert S**, Worringer U, Backe J, Rückert EM, White K, Faller H, Grimm T, Caffier H, Chang-Claude J, Weber B. Simultaneous interdisciplinary counseling in German breast/ovarian cancer families: first experiences with patient perceptions, surveillance behavior and acceptance of genetic testing. *Genet Couns* 2000;**11**:127-46.