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Insurance reimbursement for risk-reducing mastectomy and oophorectomy in women with *BRCA1* or *BRCA2* mutations

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Purpose: Risk-reducing surgery is an important option for women with *BRCA1* and *BRCA2* mutations. There are reports in the literature that insurance reimbursement for these procedures varies greatly. Because health insurance coverage significantly affects medical decision-making, current information regarding reimbursement practices of third-party payers is needed. **Methods:** Retrospective study of hospital billing records of 38 women with documented *BRCA1* or *BRCA2* mutations who underwent either a risk-reducing mastectomy or a risk-reducing oophorectomy between March 1, 1997, and July 30, 2000. **Results:** Complete billing and reimbursement information was available for 35 women undergoing a total of 39 risk-reducing surgeries. A total of 38 of 39 (97%) risk-reducing surgeries were covered in full, less applicable coinsurance and deductibles. The rate of insurance reimbursement did not vary with type of insurance, personal history of cancer, or type of procedure. **Conclusion:** Insurance carriers reimbursed the vast majority of *BRCA* mutation carriers undergoing risk-reducing surgery. ***Genet Med* 2001:3(6):422–425.**

Key Words: *genetic counseling, insurance,* BRCA1, BRCA2*, prophylactic surgery*

Women who are heterozygous for mutations in *BRCA1* or *BRCA2* have a 40% to 80% lifetime risk of breast cancer and a 25% to 60% lifetime risk of ovarian cancer.[1,2] Various cancer screening and risk-reduction strategies have been proposed, including increased surveillance, chemoprophylaxis, and risk-reducing surgical options.[3–6]

Risk-reducing surgeries have shown great promise for women at increased hereditary risk based on family history and in women with documented *BRCA* mutations. A retrospective study of risk-reducing mastectomy in high-risk women demonstrated a breast cancer risk reduction of $> 90\%$.[6] Early data evaluating risk-reducing oophorectomy in women with *BRCA* mutations showed an odds ratio for development of ovarian cancer of 0.002 to 0.12 after risk-reducing surgery.[7] Additionally, several groups have suggested that risk-reducing oophorectomy in *BRCA* mutation carriers and other high-risk women significantly decreases risk of subsequent breast cancer.[8,9] Although the optimal risk-reduction strategy for a woman with a *BRCA* mutation clearly needs to be individualized, risk-reducing mastectomy and oophorectomy need to be considered as part of the continuum of management options.

BRCA mutation carriers considering risk-reducing surgery have several concerns. In addition to physical, psychological, sexual, and cultural issues, insurance and financial considerations may have an important impact. There is ample documentation in the literature that coverage decisions by health insurers play a significant role in utilization of new technologies.[10,11] However, there are no published studies that address the actual reimbursement experience of high-risk women undergoing risk-reducing surgeries. Additionally, there are isolated reports that women with familial cancer syndromes are being denied coverage for risk-reducing surgeries.[12,13] The only published study evaluating health insurance coverage for risk-reducing mastectomy or oophorectomy was a survey of health plan medical directors that found that 10% to 11% of private insurers and 48% to 50% of governmental carriers had policies specifically denying coverage for risk-reducing surgery in the setting of a *BRCA* mutation. An additional 52% to 64% of private carriers and 40% of governmental carriers had no identifiable policy regarding coverage of risk-reducing surgery in women with *BRCA* mutations.[13] The authors speculated that without identifiable policies regarding risk-reducing surgery in high-risk individuals, this critical health care decision may be subject to arbitrary criteria, resulting in substantial variation in utilization of risk-reducing surgery. This study is the first systematic attempt to evaluate the actual insurance reimbursement ex-

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perience of women with *BRCA* mutations who have undergone a risk-reducing mastectomy or oophorectomy.

METHODS

Subjects were ascertained from a cohort of 219 women identified from June 1, 1995, through July 30, 2000, as having a deleterious mutation in *BRCA1* or *BRCA2* and are currently enrolled in an ongoing follow-up study by the Clinical Genetics Service at Memorial Sloan-Kettering Cancer Center (MSKCC). The MSKCC Institutional Review Board approved the study design, and all patients signed a written informed consent. Patients enrolled in this study were initially contacted by phone and asked to complete a structured questionnaire at a median of 11.6 months after genetic testing. Subjects were then subsequently contacted annually by letter to obtain further follow-up information by means of a written questionnaire. During each of these contacts, the participants provided information addressing, among other issues, current screening practices, use of chemoprophylaxis, and whether they have undergone a risk-reducing surgery. Information was also gathered regarding institutions where surveillance and/or risk-reducing surgeries were performed as well as third-party payment for these procedures.

Eighty-four women in this cohort identified themselves as having undergone a total of 28 risk-reducing mastectomies and 73 risk-reducing oophorectomies between March 1, 1997, and July 30, 2000. Of this group, 41 patients identified themselves as having a total of 34 risk-reducing oophorectomies, 10 risk-reducing mastectomies, and 2 simultaneous risk-reducing mastectomy/oophorectomies performed at MSKCC. For patients who had a risk-reducing surgery at MSKCC, information on type of surgery, age at surgery, and personal and family history of cancer was abstracted from the questionnaire and medical records. Preoperative imaging and pathology were also reviewed. Two women who underwent oophorectomy were excluded because complex adnexal masses were seen on preoperative ultrasounds. One woman who underwent mastectomy was excluded because a preoperative breast biopsy demonstrated lobular carcinoma-in-situ.

Hospital billing records were reviewed for each of these procedures. Information on total hospital charges, amount of insurance reimbursement, out of pocket charges, and type of insurance was abstracted. Physician professional charges were not included in our analysis. Two patients who underwent risk-reducing oophorectomy and one patient who underwent simultaneous risk-reducing mastectomy and oophorectomy were excluded because insurance reimbursement data were not available.

All patients in the study submitted hospital charges to their insurance carrier. Insurance reimbursement was classified into three groups: (1) insurance paid claim in full (less applicable coinsurance and deductibles), (2) partial reimbursement (i.e., less reimbursement than MSKCC would receive for the same procedure for therapeutic indications), and (3) no reimbursement. Rates of insurance reimbursement were obtained for the entire cohort. Patients were then stratified by type of insurance, type of procedure, and personal history of cancer. The stratified groups were compared with each other using the Fisher exact test. All statistical analysis was performed using SPSS for Windows software version 10.0 (SPSS, Chicago, IL).

RESULTS

A total of 35 patients undergoing a total of 39 procedures met the inclusion criteria and had complete billing records available. Patient demographic data are listed in Table 1.

Thirty-eight of 39 (97%) procedures were reimbursed in full, less applicable coinsurance and deductibles. A single patient with a history of prior unilateral breast cancer and one first-degree relative with premenopausal breast cancer was denied reimbursement. No patients were partially reimbursed. When patients were stratified according to type of insurance, personal history of cancer, or type of procedure, no significant differences in the rate of reimbursement were noted. Results are summarized in Table 2.

Table 1
Patient demographics

Mean age at risk-reducing surgery	44.54 (range, 29–60)
Risk-reducing mastectomy	40.18 (range, 29–58)
Risk-reducing oophorectomy	46.24 (range, 34–60)
History of prior cancer	
Breast	25 (71%)
Ovary	1 (3%)
Mean number of 1st- or 2nd-degree relatives with breast or ovarian cancer	2.23 (range, 0–4)
Mutation	
BRCA1	23 (66%)
BRCA2	12 (34%)
Type of surgery	
Risk-reducing mastectomy	11[a]
Unilateral	5 (45%)
Bilateral	6 (55%)[b]
Risk-reducing oophorectomy	29[a]
Type of insurance	
Indemnity	19 (54%)
Managed Care	16 (44%)
Governmental	0 (0%)

[a] Includes one simultaneous risk-reducing oophorectomy/unilateral mastectomy.
[b] Includes one patient with a prior unilateral breast cancer treated conservatively.

Table 2
Percentage of procedures reimbursed by third-party payers

	N	Full reimbursement[a] (%)	Partial reimbursement (%)	No reimbursement (%)
Type of insurance				
Indemnity	22	95	0	5
Managed care	17	100	0	0
Type of procedure				
Oophorectomy	29	97	0	3
Mastectomy	11	100	0	0
Prior history of cancer				
Present	30	97	0	3
Absent	9	100	0	0
All procedures	39	97	0	3

[a]Less coinsurance and deductibles.

DISCUSSION

A total of 97% of risk-reducing procedures performed at MSKCC on our study group between March 1, 1997, and July 30, 2000 were covered in full, less applicable coinsurance and deductibles. The medical record of the single patient whose insurance reimbursement was denied was notable for two reasons. Her procedure occurred in the first half of 1997. At this time, there was very limited data regarding the efficacy of prophylactic oophorectomy in *BRCA* mutation carriers. It is possible, given the paucity of data available at this time, her insurance company did not conclude that her oophorectomy was a medically indicated procedure. Second, it is likely, as in the case of most of our patients, the third-party payer was not notified that the patient had a deleterious gene mutation. Risk of insurance and employment discrimination based upon results of genetic testing has been extensively commented on in the literature.[14–16] As a result of this possibility, all genetic testing at MSKCC for mutations in *BRCA1* and *BRCA2* is offered under research protocols providing the protection of federal Certificates of Confidentiality. Patients are also extensively counseled regarding the potential risks and benefits of revealing mutation status, including the possibility that not revealing mutation status may result in denial of insurance coverage for risk-reducing surveillance or surgical options.

Our study design has several limitations. First, the participants all received their care at a tertiary cancer center, and their experience may not reflect care received in other settings. Although insurance reimbursement information was only available on 28 of 49 risk-reducing procedures performed at other institutions, study participants reported that 26 of 28 (93%) surgeries were reimbursed for at least 80% of charges. Second, as this design was retrospective, it may have selected out patients who desired risk-reducing surgery but could not obtain preauthorization for the procedure from their insurance companies. By excluding these patients, we could have introduced a bias toward our observed results. We believe if this effect is present, it is likely to be small, as no patient in our ongoing follow-up study of almost 220 women with *BRCA* mutations reported that they desired a risk-reducing surgery but did not proceed because of inability to obtain insurance preauthorization. Third, in the majority of patients, *BRCA* mutation status was not documented in the medical or billing records for the reasons discussed above. As most of our patients were at increased risk by family history alone, the study design may more accurately reflect third party reimbursement in the context of a strong family history of cancer rather than reimbursement in the context of a documented *BRCA* mutation. Lastly, because no patient in our study participated in Medicaid or Medicare, we are unable to comment on reimbursement practices of these programs.

Our results indicate that private third-party payers reimbursed almost all *BRCA* mutation carriers undergoing risk-reducing mastectomy or oophorectomy at MSKCC. Risk-reducing surgical interventions are likely to become more widespread as genetic counseling and testing for inherited cancer predisposition syndromes becomes more available. For this reason, well designed, prospective studies addressing access limitations to risk-reducing interventions will be needed to address this important public health issue in the years ahead.

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