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Aspects of Breast cancer

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13. ABSTRACT (Maximum 200) This report summarizes activities during the second year of a four year predoctoral research training program in biopsychosocial aspects of breast cancer. Three research trainees were supported during the initial year of the training program. One of these trainees was supported during the first year of the training program while the remaining two were new appointees. Research training was provided by a multidisciplinary faculty of six. A monthly meeting of program trainees and faculty was held to facilitate oversight of trainee research activities and discussion of breast-cancer related research. Trainees participated in a variety of group and individual research projects related to breast cancer under the supervision of program faculty. Trainees participated in all phases of the research enterprise including protocol development, obtaining approval for use of human subjects, data collection, data preparation, entry, and analysis, and manuscript preparation. Research activities conducted during the second year of the training program centered around the UK Multidisciplinary Breast Care Center. However, a foundation was developed for research activities to be expanded to include projects involving the bone marrow transplant program and the hereditary breast and ovarian cancer clinic at the University of Kentucky.				
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FOREWORD

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Michael Andrew Jones 8-16-96
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5. INTRODUCTION

High quality research investigating various psychosocial and behavioral aspects of breast cancer has the potential to reduce breast cancer-related mortality as well as improve quality of life following breast cancer. Critical to the performance of high quality research in this area is the recruitment and training of new researchers. This report summarizes activities and accomplishments during the second year of a four year predoctoral research training program in biopsychosocial aspects of breast cancer. The training program is centered in the Department of Behavioral Science, a basic science department in the University of Kentucky College of Medicine. A training faculty of six is drawn from three academic units within the College of Medicine (Behavioral Science, Medicine-Hematology/Oncology, and Nursing).

6. BODY

The second year of the research training program began on August 15, 1995. A total of three predoctoral trainees were appointed and began one year terms as of that date. One of these three appointees, Janet Carpenter, a doctoral student in Nursing, was a reappointee from the first year of the training program. The two new trainees appointed for the second year both possessed Masters degrees in their respective fields and were pursuing doctoral studies in the Graduate School at the University of Kentucky. One of the new appointees, Lauren Cunningham, was pursuing a doctoral degree in Clinical Psychology and already possessed some prior research experience in an oncology setting. The other new appointee, Robin Lightner, was pursuing a doctoral degree in Social Psychology. Funding from the training program grant provided a monthly stipend as well as annual graduate school tuition for all three predoctoral trainees.

Shelly Curran, Ph.D., one of the two appointees from the initial year of the training program, completed her doctoral studies and on September 1, 1995 began a clinical internship at the University of Pittsburgh Western Psychiatric Institute under the direction of Dennis Turk, Ph.D.. She completed her dissertation, entitled "Multidimensional Assessment of Fatigue Following Breast Cancer Treatment: A Controlled Comparison" in July of 1996. She has submitted one manuscript for publication based upon her dissertation research.

Janet Carpenter, R.N., Ph.D., a research trainee during both the first and second years of the training program, completed her dissertation entitled "Self Esteem and Well-Being in Women With Breast Cancer and Age-Matched Comparison Women" in June of 1996. She has accepted a position as an NIMH postdoctoral research trainee at the University of Kentucky. This position is allowing her to receive additional postdoctoral research training in behavioral oncology under the direction of Michael Andrykowski, Ph.D. She has submitted two manuscripts for publication based upon her dissertation research.

The research training program consists of six basic components: (1) training in research design, methods, and analysis; (2) supervised experience in breast cancer-related research; (3) training in the responsible (i.e., ethical) conduct of research; (4) enculturation to the breast cancer care environment; (5)

tutorial in biopsychosocial research in breast cancer; and (6) graduate level coursework. Each of these components was effectively implemented during the second year of the training program.

A monthly meeting of the training program faculty and predoctoral trainees continued to be held during the second year of the training program. Other faculty, graduate students, and postdoctoral fellows interested in biopsychosocial breast cancer research were also invited to attend on an ad hoc basis. This meeting lasted for roughly 75-90 minutes each month. This meeting provided: (a) an opportunity for all members of the training program to keep abreast of the research activities of the three trainees; (b) a forum for training faculty and trainees to discuss recent and ongoing research in biopsychosocial aspects of breast cancer; and (c) an opportunity for faculty and trainees to discuss ideas leading to the development of new breast-cancer related research projects at the University of Kentucky.

During the second year of the training program, all three predoctoral research trainees were actively involved in specific research projects under the supervision of training program faculty. These "communal" research projects included: (a) a comparison of psychological adjustment, quality of life, and fatigue in women with breast cancer and age-matched women with benign breast problems; (b) an investigation of symptoms of post-traumatic stress disorder (PTSD) in women previously treated for early-stage breast cancer; (c) an investigation of self-reported symptoms of postchemotherapy rheumatism following adjuvant chemotherapy for breast cancer; (d) investigation of breast cancer risk perceptions, "objective" risk, and breast cancer detection behavior in women with benign breast disease, (e) a population survey of Kentucky residents regarding knowledge of hereditary risk for breast and ovarian cancer and interest in clinical testing for that risk, and (f) a population survey of Kentucky residents regarding attitudes toward participation in oncologic clinical trials. Trainee involvement in these communal research projects ranged across all phases of the research enterprise including research protocol development, preparation of requests for approval for use of human subjects, data collection, data preparation, entry, and analysis, and finally manuscript preparation.

In addition to the communal research projects cited above, one of the trainees (Janet Carpenter, R.N., Ph.D.) developed and implemented her own breast cancer-related research project. This research project served as the research dissertation necessary to meet requirements for her doctoral studies in Nursing. This individual dissertation research project was conducted under the supervision of training program faculty with two members of the training program faculty serving as members of the dissertation committee. Dr. Carpenter's dissertation was a detailed assessment of changes in self-concept and self-esteem following treatment for breast cancer ($n=65$). Identical data was collected from an age-matched comparison group of healthy women ($n=65$). Dr. Carpenter assumed full responsibility for all aspects of the development and implementation of this research project.

Each of the communal research projects "a" through "d" listed above, as well as the individual dissertation research project described above, utilized women treated for breast cancer or benign breast problems at the Multidisciplinary Breast Care Center at the University of Kentucky Chandler Medical Center. In

order to identify and enroll study eligible women, all of the trainees have been required to work closely with the breast surgeons and medical oncologists caring for these women at the Breast Care Center. This has resulted in trainees spending considerable time in the Breast Care Center, thus becoming very familiar with the milieu and culture in which breast cancer treatment is embedded.

A number of manuscripts have stemmed directly from research activities supported by the training program. Three manuscripts are published or in press. These are listed below and copies are provided in the Appendix. Several more have been submitted for publication and are presently under peer review. These are listed at the end of this section. Finally, during the second year of the training program trainees have had the opportunity to participate in a number of poster and paper presentations at professional conferences. These are also listed at the end of this section.

During the early spring of 1996, recruitment of additional predoctoral research trainees to be appointed for the third year of the training program commenced. Lauren Cunningham was reappointed to a second year of training beginning August 15, 1996. Robin Lightner chose to accept an NIMH research training fellowship and was thus not reappointed to the training program. Janet Carpenter, R.N., Ph.D., completed her dissertation and began postdoctoral research training at the University of Kentucky. Thus, availability of two one-year predoctoral research trainee positions was advertised throughout both the medical center and main campuses at the University of Kentucky. A total of 8 completed applications were received. These 8 applications spanned a variety of disciplines including Nursing, Anthropology, Communications, and various subdisciplines of Psychology including counseling, clinical, and social psychology. Following review of the entire pool of applicants two individuals were offered training positions for the third year of the training program. Both Jamie Studts, a doctoral candidate in Clinical Psychology, and Matt Cordova, a doctoral candidate in Clinical Psychology accepted these offers of appointment. They began their appointments on July 1, 1996 and joined Lauren Cunningham to form a very solid group of three trainees for the third year of the training program.

MANUSCRIPTS PUBLISHED OR IN PRESS

Andrykowski, M.A., Curran, S.L., Studts, J.L., Cunningham, L., Carpenter, J.S., McGrath, P.C., Sloan, D.A., & Kenady, D.E. (in press). Psychological adjustment and quality of life in women with breast cancer and benign breast problems: A controlled comparison. Journal of Clinical Epidemiology.

Andrykowski, M.A., Munn, R.K., & Studts, J.L. (in press). Interest in learning of a personal genetic predisposition for cancer: Results of a general population survey. Preventive Medicine.

Cordova, M.J., Andrykowski, M.A., Kenady, D.E., McGrath, P.C., Sloan, D.A., & Redd, W.H. (1995). Frequency and correlates of PTSD-like symptoms following treatment for breast cancer. Journal of Consulting and Clinical Psychology, 63, 981-986.

MANUSCRIPTS SUBMITTED FOR PUBLICATION, PRESENTLY UNDERGOING PEER REVIEW

Andrykowski, M.A., Curran, S.L., & Lightner, R. (1996). Fatigue following treatment for breast cancer: A controlled comparison. Manuscript submitted for publication.

Carpenter, J.S. (1996). Applying the Cantril methodology to study self-esteem: Psychometrics of the self-anchoring self esteem scale. Manuscript submitted for publication.

Carpenter, J.S. (1996). Self-esteem and well-being among women with breast cancer and age-matched comparison women. Manuscript submitted for publication.

Curran, S.L., & Andrykowski, M.A. (1996). Diurnal patterns of fatigue, mood, and pain, following breast cancer treatment. Manuscript submitted for publication.

Curran, S.L., Andrykowski, M.A., Studts, J.L., Cunningham, L., Carpenter, J.S., McGrath, P.C., Sloan, D.A., & Kenady, D.E. (1996). Self-reported joint pain and swelling following breast cancer treatment: Evidence for postchemotherapy rheumatism. Manuscript submitted for publication.

Valentino, J., Andrykowski, M.A., Lightner, R., & Wood, T. (1996). Population attitudes toward oncology clinical trials. Manuscript submitted for publication.

PAPER AND POSTER PRESENTATIONS AT PROFESSIONAL CONFERENCES

Carpenter, J.S. (August, 1996). Self-esteem and well-being among women with breast cancer and age-matched comparison women. Poster to be presented at the 9th International Conference on Cancer Nursing, Brighton, Sussex, United Kingdom.

Carpenter, J.S. (May, 1996). Self-esteem and well-being among women with breast cancer and age-matched comparison women. Poster presented at the Oncology Nursing Society Congress, Philadelphia, PA.

Carpenter, J.S. (February, 1996). Self-esteem and well-being among women with breast cancer and age-matched comparison women. Poster presented at the Southern Nursing Research Society Conference, Miami, FL. (awarded Honorable Mention)

Cunningham, L., & Andrykowski, M.A. (March, 1996). Psychological distress and perceived risk in women with fibrocystic breast disease. Paper presented at the Fourth International Congress of Behavioral Medicine, Washington, D.C.

Curran, S.L., & Andrykowski, M.A. (March, 1996). A controlled multidimensional assessment of fatigue following breast cancer treatment. Paper presented at the Fourth International Congress of Behavioral Medicine, Washington, D.C.

7. CONCLUSIONS

Each of the six components of the research training program were effectively implemented during the second year of the training program. All three trainees received supervised, "hands on" experience in all aspects of conducting biopsychosocial breast cancer-related research. In addition, all three trainees had the opportunity to participate in a variety of specific research projects, thus increasing the breadth of their experience. Finally, all three trainees had the opportunity for extensive interaction with both patients and health providers in the breast cancer care setting.

During the third year of the project, it is hoped that the breadth of research activities available to trainees will be expanded. Research activities during the second year revolved primarily around patient populations from the Multidisciplinary Breast Care Center at the University of Kentucky Chandler Medical Center. We have already expanded the number of clinical sites available for research to include the bone marrow transplantation program and hereditary breast and ovarian cancer clinic at the University of Kentucky. A research protocol has already been developed and approved to examine quality of life in women undergoing autologous bone marrow transplantation. Additionally, data is already being collected regarding individuals' interest and expectations for risk counseling and testing regarding hereditary breast and ovarian cancer. Finally, we are working to extend research training activities to include additional biological endpoints such as immune functioning or estrogen response to stress.

8. REFERENCES

None.

9. APPENDIX

Three publication have resulted directly from training program research activities at the time of this writing. One of these has been published while two are still in press. Copies of these are included in the appendix. Copies of manuscripts presently undergoing peer review will be included in future annual reports should they be accepted for publication.

Frequency and Correlates of Posttraumatic-Stress-Disorder-Like Symptoms After Treatment for Breast Cancer

Matthew J. Cordova, Michael A. Andrykowski,
Daniel E. Kenady, Patrick C. McGrath
and David A. Sloan
University of Kentucky College of Medicine

William H. Redd
Memorial Sloan-Kettering Cancer Center

Diagnosis of life-threatening illness now meets *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; American Psychiatric Association, 1994) criteria for traumatic stressor exposure for posttraumatic stress disorder (PTSD). Quality of life (QOL) and PTSD-like symptoms were assessed in 55 women posttreatment for breast cancer. PTSD symptom measures included the PTSD Checklist—Civilian Version (PCL-C) and the Impact of Events Scale. QOL was assessed using the 20-item Medical Outcomes Study Questionnaire. PTSD symptomatology was negatively related to QOL, income, and age. Time since treatment, type of cytotoxic treatment, and stage of disease were unrelated to PTSD symptoms. With suggested criteria for the PCL-C, 5% to 10% of the sample would likely meet *DSM-IV* PTSD criteria. Findings suggest that in survivors of breast cancer, these symptoms might be fairly common, may exceed the base rate of these symptoms in the general population, are associated with reports of poorer QOL, and, therefore, warrant further research and clinical attention.

Criteria for diagnosis of posttraumatic stress disorder (PTSD) have been revised in the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; American Psychiatric Association, 1994). Significantly, "being diagnosed with a life-threatening illness" now meets the criterion for "exposure to an extreme traumatic stressor" fundamental to the diagnosis of PTSD (American Psychiatric Association, 1994, p. 424). Expansion of the "traumatic experience" criterion from the *DSM* (3rd ed., revised; *DSM-III-R*; American Psychiatric Association, 1987) raises significant questions concerning the frequency and nature of PTSD and PTSD-like symptoms among survivors of life-threatening disease, including cancer survivors.

Literature on PTSD in survivors of life-threatening illness is sparse; however, several studies indicate members of some medical populations, including burn patients (Powers, Cruse, Daniels, & Stevens, 1994) and individuals experiencing cardiac events such as myocardial infarction, heart catheterization, or coronary artery

bypass surgery (Doerfler, Pbert, & DeCosimo, 1994; Kutz, Shabtai, Solomon, Neumann, & David, 1994), may experience pervasive anxiety or other PTSD-like symptoms. Few studies shed light on the presence of PTSD-like symptoms in cancer patients. Intrusive thoughts concerning bone marrow transplantation (BMT) and avoidance of treatment reminders have been reported in pediatric BMT recipients (Heiney, Neuberg, Myers, & Bergman, 1994; Stuber, Nader, Yasuda, Pynoos, & Cohen, 1991). Lesko, Ostroff, Mumma, Mashberg, and Holland (1992) found that acute leukemia patients ($n = 70$) who had undergone either BMT or conventional antileukemic therapy reported higher levels of PTSD-like symptoms than physically healthy individuals. Cella and Tross (1986) found that male survivors of Hodgkin's disease evidenced more avoidant thinking about illness than healthy control patients. Finally, Kornblith et al. (1992) found that intrusive thoughts and avoidance of treatment reminders in individuals with Hodgkin's disease were inversely related to time since treatment completion.

Together, this research supports a link between life-threatening illness or highly stressful medical procedures and the development of PTSD or PTSD-like symptoms. However, few studies have focused explicitly on assessment of PTSD symptoms after life-threatening disease. Consequently, assessment instruments developed with the use of more traditional PTSD populations have not been used. Also, little is known regarding variables that might characterize survivors of life-threatening illness most at risk for developing PTSD or PTSD-like symptoms. Potential risk factors can be gleaned from several sources. First, PTSD research with combat veterans, rape victims, or victims of natural disasters has identified several risk factors including degree of life threat, duration of trauma, displacement from home or community, potential for recurrence, and exposure to death or destruction (Wilson, Smith, & Johnson, 1985). Some of these factors, such as degree of life threat or potential for recurrence, have parallels in life-threat-

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This study was supported in part by predoctoral research training grants from the National Institute of Mental Health (MH-15730) and the U.S. Army Medical Research and Development Command (AIBS #174).

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Table 1
Descriptive Statistics and Internal Consistencies for IES and PCL-C Scale and Subscales

Measure	<i>M</i>	<i>SD</i>	Range	α
IES				
Total	16.4	18.0	0-69	.93
Avoidance	9.0	10.6	0-36	.88
Intrusions	7.4	9.1	0-35	.91
PCL-C				
Total	27.1	12.7	17-76	.94
Avoidance	3.4	2.2	2-10	.66
Intrusions	6.4	3.6	5-20	.89
Numbing	6.0	3.2	5-20	.77
Arousal	11.3	5.1	5-30	.80

Note. IES = Impact of Events Scale; PCL-C = Posttraumatic Stress Disorder Checklist—Civilian Version.

in Table 1. To identify specific types of PTSD-like symptoms reported in our sample, we determined the frequency of endorsement of items on both the IES and the PCL-C. Endorsement of an IES item was defined as indicating that a symptom occurred "often" during the past week. (This is the most extreme response option on the IES.) IES items most frequently endorsed were "I tried to remove it from memory" (29%), "I tried not to think about it" (22%), and "any reminder brought back feelings about it" (16%). IES items least frequently endorsed were "I had dreams about it" (4%) and "I was aware I still had a lot of feelings about it, but didn't deal with them" (4%). Similarly, the percentage of respondents endorsing each item on the PCL-C was also determined. Endorsement of a PCL-C item was defined as rating a symptom as bothersome during the past month either "quite a bit" or "extremely." PCL-C items most frequently endorsed included "being superalert, or watchful or on guard" (44%), "trouble falling or staying asleep" (28%), and "having difficulty concentrating" (24%). PCL-C items least frequently endorsed were "repeated disturbing dreams of cancer treatment or your experience with cancer" (4%), "feeling very upset when something happened that reminded you of cancer treatment or your experience with cancer" (8%), and "feeling distant or cut off from other people" (6%).

Responses to the open-ended questions on the PCL-C indicated that of the 27 participants (49%) who indicated that they experienced repeated, disturbing memories of cancer treatment or their experience with cancer, the most common memories were related to side effects of surgery ($n = 13$), fears of recurrence ($n = 10$), and side effects of chemotherapy ($n = 8$). The 4 participants (7%) who reported having repeated, disturbing dreams of cancer treatment or their experience with cancer identified fears of recurrence, fears of death, and both surgery and adjuvant treatment side effects as the most common themes. Of the 19 participants (35%) who indicated they experienced physical reactions when something reminded them of cancer treatment or their experience with cancer, the most common reactions were nausea ($n = 13$), heart palpitations ($n = 8$), and general feelings of panic ($n = 7$). Prominent triggers of these physical reactions were being near or in the hospital in which they underwent treatment ($n = 7$), thoughts about chemotherapy ($n = 6$), and thoughts of recurrence ($n = 5$).

Table 2 shows the Pearson product-moment correlations among scales and subscales on the IES and PCL-C. Total scores on the IES and PCL-C were highly correlated ($r = .88, p < .01$). The IES and PCL-C avoidance subscales were significantly correlated ($r = .64, p < .01$), as were the IES and PCL-C "intrusions" subscales ($r = .89, p < .01$).

To examine the relationship between indices of PTSD-like symptomatology and QOL, we computed Pearson product-moment correlations between scale and subscale scores on the IES and PCL-C and the six subscales on the MOS-20. MOS-20 indices were significantly negatively correlated with reports of PTSD-like symptoms. Intercorrelations ranged from $-.33$ to $-.80$ (all $ps < .05$) with 40 of the 48 correlations exceeding .50 in absolute value. Total scores on the IES and PCL-C were most strongly related to the MOS-20 Social Functioning ($r = -.76, p < .01$ and $r = -.82, p < .01$, respectively) and Mental Health ($r = -.77, p < .01$ and $r = -.85, p < .01$, respectively) subscale scores.

Univariate correlations between IES and PCL-C total scores and demographic and treatment variables are presented in Table 3. Significant negative relationships were found between both IES and PCL-C total scores and income ($r = -.27, p < .05$, and $r = -.38, p < .01$, respectively), education ($r = -.28, p < .05$, and $r = -.37, p < .01$, respectively), and age ($r = -.28, p < .05$, and $r = -.27, p < .05$, respectively). Time since treatment was inversely related only to IES total scores ($r = -.28, p < .05$). To identify variables related to PTSD symptomatology, we conducted a pair of simultaneous multiple regression analyses (Table 4). Dependent variables were total scores on the IES and PCL-C. The six predictor variables included in the analyses were chosen based on both our specific hypotheses (age, disease staging, type of treatment) and on univariate correlation results (income, education, time since treatment). Disease stage was dichotomized as Stage I versus Stage II and III disease. Type of treatment was dichotomized as surgery alone versus surgery plus chemotherapy or radiotherapy. The six predictor variables accounted for 25% of the variance in IES total scores, $F(6, 48) = 2.67, p < .05$, with age as the lone significant predictor of IES total scores ($\beta = -.28$), $t(48) = -2.04, p < .05$. Younger women reported greater PTSD-like symptoms. Similarly, the six predictor variables accounted for 31.6% of the variance in total scores on the PCL-C, $F(6, 48) = 3.70, p < .01$. Both income ($\beta = -.34$), $t(48) = -2.53, p < .02$,

Table 2
Univariate Correlations Among Scales and Subscales on the IES and the PCL-C

Measure	1.	2.	3.	4.	5.	6.	7.	8.
1. IES total	—							
2. IES-Av	.93	—						
3. IES-I	.90	.68	—					
4. PCL-C total	.88	.72	.90	—				
5. PCL-Av	.69	.64	.63	.79	—			
6. PCL-I	.87	.72	.89	.92	.64	—		
7. PCL-N	.75	.60	.79	.89	.71	.75	—	
8. PCL-Ar	.80	.64	.85	.94	.63	.84	.75	—

Note. $N = 55$. IES = Impact of Events Scale; PCL-C = Posttraumatic Stress Disorder Checklist—Civilian Version; Av = Avoidance; I = Intrusions; N = Numbing; Ar = Arousal. All $ps < .01$.

ening illness. Second, recent behavioral conceptualizations of the etiology of PTSD and PTSD-like symptoms suggest that greater intensity of the traumatic stressor is associated with increased likelihood of developing these stress reactions (Green, 1990; Green, Grace, Lindy, Gleser, & Leonard, 1990). Thus, exposure to more prolonged, extensive, or aversive medical treatment might be associated with increased risk for PTSD or PTSD-like symptoms in survivors of life-threatening illness. Finally, research examining psychological adjustment in cancer survivors suggests that there are risk factors for general poor adjustment, such as poor social support (e.g., Irvine, Brown, Crooks, Roberts, & Browne, 1991) and younger age (e.g., Vinokur, Threalt, Vinokur-Kaplan, & Satariano, 1990). These factors might be linked to risk of PTSD or PTSD-like symptoms as well.

The present study is an initial examination of the frequency and correlates of PTSD-like symptoms after the diagnosis and treatment of breast cancer. On the basis of the preceding review of the literature, it is hypothesized that women who are more likely to display PTSD-like symptoms are younger, are diagnosed at a more advanced stage of disease, and receive more extensive cytotoxic treatment.

Method

Sample

Participants were patients at the Comprehensive Breast Care Center at the University of Kentucky Chandler Medical Center. Women eligible for study participation were (a) >18 years of age; (b) diagnosed with Stage I, II, or III-A carcinoma of the breast; (c) 6 to 60 months post-completion of all primary breast cancer therapy (i.e., surgery, chemotherapy, radiotherapy); and (d) participants in a previous study of post-treatment quality of life (QOL). Ninety-two women participated in a previous study of QOL after treatment for breast cancer. Less than 10% of eligible women did not participate in this study; thus, the 92 participants in the previous study are likely to be representative of breast cancer patients seen at this clinic. After participation in this previous study, 77 of 92 women (84%) indicated interest in being contacted regarding participation in future research. Of these, 62 (81%) consented to participate in the present study. Nonparticipants ($n = 30$) did not significantly differ from participants in the present study with respect to age, race, marital status, disease staging, or type of breast cancer treatment. They also did not differ on any measures of psychological adjustment obtained in the previous study of QOL. Participants in the present study did have significantly higher education, $t(71) = 2.40, p < .05$, and income, $t(71) = 2.22, p < .05$, than nonparticipants.

Seven of 62 women in this study were later excluded from all analyses because they did not meet eligibility criteria for disease staging ($n = 3$) or time since the completion of all breast cancer therapy ($n = 4$). These 7 participants did not differ in any respect from the 55 included in the analyses. Thus, the sample used in all analyses consisted of 55 women with a mean age of 55.5 years ($SD = 9.7$; range, 35 to 84) and a mean of 30.5 months ($SD = 16$) posttreatment for breast cancer. The sample consisted of 51 Caucasian and 4 African American women, and 60% were married. Forty percent had a high school education, 22% had some college or a college degree, and 38% had some postgraduate study or a postgraduate (or professional) degree. Twenty-six percent of the participants had an annual household income of <\$15,000, 14% had an annual household income in the \$15,000–\$30,000 range, 22% had an income within the \$30,000–\$50,000 range, and 16% had an annual household income of >\$50,000.

Percentage of disease stage at initial diagnosis was as follows: Stage I, 62%; Stage II, 34%; Stage III-A, 4%. All patients had undergone either

modified radical mastectomy (69%), radical mastectomy (2%) or lumpectomy with axillary node dissection (29%). Additional adjuvant treatment was received by 78% of patients consisting of chemotherapy ($n = 21$), radiotherapy ($n = 17$), or a combination of chemotherapy and radiotherapy ($n = 5$). Chemotherapy regimens included cyclophosphamide, methotrexate, and 5-Fluorouracil (5-FU; $n = 9$), cyclophosphamide and doxorubicin ($n = 9$); 5-FU, cyclophosphamide, and doxorubicin ($n = 4$); and 5-FU, cyclophosphamide, doxorubicin, and methotrexate ($n = 4$). Finally, 27 women (49%) were receiving oral hormonal therapy (i.e., tamoxifen) at the time of study participation.

Procedure

Eligible women received a letter describing the study and returned a signed consent form by mail. All telephone interviews were conducted by Matthew J. Cordova, a doctoral-level student who was not involved in the women's medical care. Interviews were brief ($M = 30$ min), and participants were debriefed at the conclusion. Demographic and medical record information was already available for all study participants from the previous QOL study.

Interview Measures

During the interview, all women completed the Medical Outcomes Study 20-Item Short-Form General Health Survey (MOS-20), the Impact of Events Scale (IES), and the PTSD Checklist—Civilian Version (PCL-C). The MOS-20 is a measure of QOL in medical populations and yields subscale scores for physical and mental health, social and role functioning, health perceptions, and limitations to current functioning (Stewart, Hays, & Ware, 1988). The IES is a measure of current subjective distress that has been used in evaluating stress reactions after cancer treatment (e.g., Cella & Tross, 1986; Horowitz, Wilner, & Alvarez, 1979; Lesko et al., 1992). The IES yields subscale scores for intrusive and avoidant cognitions, as well as a total distress score. Respondents indicate how often they have experienced a number of symptoms during the last week on a 4-point scale, ranging from *not at all* (1) to *often* (4). The PCL-C was developed to assess PTSD in noncombat veteran populations (Weathers, Huska, & Keane, 1991). The PCL-C consists of 17 items that correspond to *DSM-IV* symptoms of PTSD. Respondents indicate how much they have been bothered by each symptom in the last month using a 5-point scale, ranging from *not at all* (1) to *extremely* (5). The PCL-C yields a total score and subscale scores for intrusive and avoidant cognitions, numbing, and arousal. Several open-ended questions were added to the version of the PCL-C used in the present study to gather more detailed information on the nature of specific PTSD-like symptoms experienced. Finally, it is important to note that participants were asked to specifically consider their experience with breast cancer and breast cancer treatment when responding to both the IES and the PCL-C.

Responses on the PCL-C can also be used to identify respondents likely to merit a formal diagnosis of PTSD. Two different sets of criteria are suggested (Weathers et al., 1991). Using the cutoff method, individuals with PCL-C total scores of 50 or more are viewed as likely to merit formal diagnosis of PTSD. The symptom method views individual items on the PCL-C as potential PTSD symptoms and defines ratings of "moderately" or greater as endorsement of a particular symptom. After *DSM-IV* criteria, individuals are considered likely candidates for a diagnosis of PTSD if they endorse one or more "reexperiencing" symptoms, three or more "avoidance or numbing" symptoms, and two or more "arousal" symptoms. Using these methods, the PCL-C has been found to have a diagnostic sensitivity of .82 and a specificity of .83 (Weathers et al., 1991).

Results

Means, standard deviations, ranges, and estimates of internal consistency for all IES and PCL-C scales and subscales are shown

Table 3
Univariate Correlations of IES and PCL-C Total Scores With
Demographic-Treatment Variables

Predictor variable	IES total	PCL-C total
Age at time of interview	-.28*	-.27*
Income level	-.27*	-.38**
Education	-.28*	-.37**
Marital status ^a	-.05	-.12
Disease staging ^b	.02	.07
Treatment ^c	.19	.12
Chemotherapy ^d	.10	.16
Surgery ^e	-.17	-.14
Time since last treatment	-.27*	-.19

Note. Point-biserial correlations were computed for marital status, disease staging, treatment, and surgery variables. Pearson product-moment correlations were computed for all others. IES = Impact of Events Scale; PCL-C = Posttraumatic Stress Disorder Checklist—Civilian Version.

^a Coded as 1 = unmarried and 2 = married. ^b Coded as 1 = Stage I; 2 = Stage II or III. ^c Coded as 1 = surgery and 2 = combination of surgery plus chemotherapy or radiation. ^d Coded as 0 = no and 1 = yes. ^e Coded as 1 = lumpectomy plus axillary node dissection and 2 = modified radical or radical mastectomy.

* $p < .05$. ** $p < .01$.

and age ($\beta = -.34$), $t(48) = -2.58$, $p < .02$, were significant predictors of PCL-C total scores. Younger and lower income women reported greater PTSD-like symptoms.

Finally, women were identified as likely to merit a formal diagnosis of PTSD using the two different sets of criteria suggested by developers of the PCL-C (Weathers et al., 1991). Using the cutoff method where PCL-C total scores in excess of 50 are considered suggestive of a PTSD diagnosis, we identified 3 of 55 women (5.5%) as likely candidates for a diagnosis of PTSD. Using the symptom method where the pattern of responses to individual PCL-C items is considered, we identified 6 of 55 women (10.9%) as likely candidates for formal diagnosis of PTSD. All 3 women meeting the criterion for PTSD diagnosis using the cutoff method also met the criterion for PTSD diagnosis using the symptom method.

To provide a more graphic and personalized view of our findings, we present brief case studies of the 3 women meeting both the symptom criteria and the cutoff criteria for the diagnosis of PTSD.

Patient A

Patient A was a 52-year-old White, married woman, with one child in the home, who was 9 months posttreatment for Stage II breast cancer. She had a grade school education and an annual income of less than \$15,000. She had undergone a modified radical mastectomy and four cycles of adjuvant chemotherapy. Her PCL-C total score was 55, and her IES total score was 65. During the interview, she said that she was frequently troubled by memories of the side effects of chemotherapy and a constant fear of cancer recurrence. She also said that whenever she thought about having breast cancer again, she became nauseated, flushed, and had heart palpitations.

Patient B

Patient B was a 46-year-old White, divorced woman, with no children in the home, who was 42 months posttreatment for Stage I breast cancer. She had a grade school education and an annual income of less than \$15,000. She had undergone a modified radical mastectomy and six cycles of adjuvant chemotherapy. Her PCL-C total score was 75, and her IES total score was 63. During the interview, she said that she was frequently troubled by memories of surgery and fears that not all the cancer was removed. She reported frequent dreams of surgery and cancer recurrence. In addition, she said that when she thought about surgery and adjuvant treatment, she experienced a "racing heart," headaches, and nausea.

Patient C

Patient C was a 47-year-old White, divorced woman, with three children in the home, who had lost her mother and sister to breast cancer and who was 10 months posttreatment for Stage I breast cancer. She had completed some high school and had an annual income of less than \$15,000. She had undergone lumpectomy and axillary node dissection surgery and one cycle of adjuvant chemotherapy. Her PCL-C total score was 76, and her IES total score was 69. During the interview, she said that she was frequently troubled by dreams of the deaths of her mother and sister and of chemotherapy. She reported that she became "shaky" and nauseous when she thought of any aspect of cancer.

Discussion

We found 5% to 10% of this unselected, nonclinical group of women posttreatment for early-stage breast cancer were likely to merit a *DSM-IV* diagnosis of PTSD. As Resnick, Kilpatrick, Dansky, Saunders, and Best (1993) reported similar prevalence rates of 12.3% for "lifetime" PTSD and 4.6% for PTSD in the previous 6 months in an unselected sample of 4,000 women

Table 4
Beta Weights for Multiple Regression Analysis of PTSD
Symptom Measures

Predictor variable	Dependent variable	
	IES	PCL-C
Time since last treatment	-.17	-.06
Income level	-.27	-.34*
Age at time of interview	-.28*	-.34*
Education	-.17	-.25
Disease staging ^a	-.12	-.06
Treatment ^b	.05	-.01

Note. $N = 55$. Multiple R s for IES and PCL-C were .500 and .562, respectively; percentages of variances accounted for were 25.0 and 31.6, respectively; and F s(6, 48) = 2.67 ($p < .05$) and 3.70 ($p < .01$). PTSD = posttraumatic stress disorder; IES = Impact of Events Scale; PCL-C = Posttraumatic Stress Disorder Checklist—Civilian Version.

^a Coded as 1 = Stage I; 2 = Stage II or III. ^b Coded as 1 = surgery; 2 = combination of surgery plus chemotherapy or radiation (or both).

* $p < .05$.

(mean age = 45 years), it is possible that our results simply reflect the base rate of PTSD in the general population of age-similar women. However, in the present study, the IES and PCL-C were keyed to assess symptoms linked to a woman's experience with breast cancer. For example, a woman was considered to be experiencing intrusive thoughts only if their content was related to her cancer experience. Had we assessed PTSD symptoms associated with any trauma, the frequency of PTSD symptoms would likely have been higher.

Although our estimated 5% to 10% frequency of PTSD in this sample suggests a link between the diagnosis and treatment of breast cancer and subsequent diagnosis of PTSD, it is likely this underestimates the frequency of PTSD-like symptoms in survivors of breast cancer. Study eligibility criteria may have excluded women suffering from acute PTSD or acute stress disorder. *DSM-IV* criteria stipulate that the diagnosis of acute PTSD can be made if symptoms have been present for between 1 and 3 months and of acute stress disorder if symptoms have been present for between 2 days and 1 month (American Psychiatric Association, 1994). Because women in this study were at least 6 months posttreatment, the occurrence of acute PTSD-like symptoms or the occurrence of symptoms that remitted before study participation were not recorded. Prospective research is necessary to clarify this issue.

We hypothesized that PTSD-like symptoms would be associated with younger age, more advanced disease, and more extensive and aggressive treatment. Only the relationship between age and PTSD-like symptoms was supported. This is consistent with previous research suggesting that younger women are more at risk for adjustment problems after breast cancer (Vinokur et al., 1990). Although our hypotheses linking more advanced disease and more extensive treatment to greater risk of PTSD-like symptoms were not borne out, our study may not have provided a good test of these hypotheses. These two variables are indirect measures of the threat or intensity of traumatic stress posed by the diagnosis and treatment of breast cancer. Future research using direct, preferably prospective, measures of the threat experienced by a woman in relation to her disease and treatment would provide a better test of the relationship between threat and subsequent PTSD-like symptoms and risk of PTSD diagnosis.

Although no specific hypotheses were advanced, lower income, and to a lesser extent less education, were associated with PTSD-like symptoms. This parallels previous research reporting a negative link between income and education and psychological distress in cancer survivors (Kornblith et al., 1992). According to Hobfoll's (1989) "resource model," psychological stress results from actual or threatened loss of resources. Survivors of breast cancer can experience actual loss or threat of loss of many kinds, including decreased physical health, financial burdens resulting from medical care, alienation from social support, and lowered self-esteem. Income and education can serve as resources that women can use to cope with these losses.

The IES and the PCL-C have been used to assess symptoms of distress in the cancer and PTSD literatures, respectively. Although the IES and PCL-C total and subscale scores were highly correlated, we did not conclude that these instruments have equal usefulness in assessing PTSD-like symptoms. Conceptually, the PCL-C contains both numbing and arousal subscales,

thus offering broader item content than the IES. These correspond to the *DSM-IV* numbing and arousal symptom subsets and therefore provide diagnostic usefulness. Empirically, the PCL-C was developed specifically for the assessment of civilian PTSD symptoms, whereas the IES was standardized on a general clinical sample of individuals seeking services for "stress reactions" (Horowitz et al., 1979; Weathers et al., 1991). Unlike the IES, the PCL-C provides norms, suggested diagnostic criteria, and methods for identifying individuals likely to merit the formal diagnosis of PTSD.

The present study has at least three limitations. First, its small, cross-sectional sample precludes statements regarding PTSD prevalence. Ideally, a prospective, longitudinal study would have been done. However, given that the *DSM-IV* PTSD stressor criterion change was recent, and that the literature on the phenomenon of PTSD in victims of life-threatening disease is sparse, it would have been unwarranted to invest resources to conduct such a study until preliminary pilot data were available. Second, face-to-face diagnostic interviews were not performed. Therefore, references to the formal diagnoses of PTSD are speculative and made only in light of suggested PCL-C diagnostic criteria (Weathers et al., 1991). Because our data suggest that PTSD-like symptoms are fairly common after treatment for breast cancer, further research incorporating formal, clinical diagnostic interviews is a logical next step. Third, the IES and the PCL-C have not been standardized on populations of women with breast cancer and, therefore, no cancer-specific norms exist. However, the IES has been used to assess distress after cancer and has been normed on patients seeking mental health services for stress reactions (Horowitz et al., 1979). Furthermore, the PCL-C was developed to assess PTSD symptoms after noncombat civilian traumatic stressors (Weathers et al., 1991) and thus would appear to be appropriate for use with individuals with life-threatening illnesses.

In conclusion, few studies have attempted to address the frequency and severity of PTSD-like symptoms in cancer survivors. This study of breast cancer survivors suggests that these symptoms might be fairly common, may exceed the base rate of these symptoms in the general population, and are associated with reports of poorer QOL. No research, however, has formally screened for PTSD diagnoses in cancer survivors. Thus, several questions remain to be addressed in future research. Can likely candidates for PTSD diagnosis be accurately identified in a group of cancer survivors using a screening questionnaire such as the PCL-C? What does a 5% to 10% frequency of likely PTSD in this sample of survivors of breast cancer suggest about the frequency of this phenomenon in survivors of other cancers? What specific stressor or stressors trigger the development of PTSD symptoms in cancer survivors? What variables are associated with PTSD-like symptoms in cancer survivors, and are these variables the same in different types of cancer? Finally, what interventions are effective in prevention and treatment of PTSD after cancer?

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1996 APA Convention *Call for Programs*

The *Call for Programs* for the 1996 APA annual convention appears in the September issue of the *APA Monitor*. The 1996 convention will be held in Toronto, Ontario, Canada, from August 9 through August 13. The deadline for receipt of program and presentation proposals is December 1, 1995. Additional copies of the *Call* are available from the APA Convention Office, effective in September. As a reminder, agreement to participate in the APA convention is now presumed to convey permission for the presentation to be audiotaped if selected for taping. Any speaker or participant who does not wish his or her presentation to be audiotaped must notify the person submitting the program either at the time the invitation is extended or before the December 1 deadline for proposal receipt.

Psychosocial Adjustment and Quality of Life in Women With Breast Cancer
and Benign Breast Problems: A Controlled Comparison

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Abstract

Comparison of psychosocial adjustment in women with breast cancer (BC) and women with benign breast problems (BBP) have been hampered by a failure to control for age differences between these groups, as well as a failure to assess positive psychosocial adaptation in addition to psychological distress. Age-matched women with breast cancer ($n=80$) and benign breast problems ($n=80$) completed measures of psychological distress, positive psychosocial adaptation, and general quality of life (QOL). BC patients had completed primary treatment for breast cancer a mean of 24.6 months prior to participation (range 6-57 months). Comparison of the BC and BBP groups indicated: (1) the BC group reported poorer physical health and functioning; (2) no differences in psychological distress; and (3) the BC group reported greater positive psychosocial adaptation, such as improved life outlook, enhanced interpersonal relationships, and deeper spiritual and religious satisfaction. Results support the theoretical position that cancer is a transitional event, that is, a traumatic event that alters an individual's assumptive world with the potential to produce long-lasting changes of both a positive as well as negative nature. This underscores the importance of using measures of both psychological distress and positive psychosocial adaptation when assessing psychological adjustment following transitional events such as breast cancer.

Psychosocial Adjustment and Quality of Life in Women With Breast Cancer
and Benign Breast Problems: A Controlled Comparison

Assessment of quality of life (QOL) and psychological distress after the diagnosis and treatment of breast cancer has been the focus of much research [1-2]. This research has consistently found that serious psychological or psychiatric disorder is rare following treatment for breast cancer. However, other firm conclusions regarding QOL or psychological distress after breast cancer treatment are difficult to draw due to diversity across studies in methodology and sample characteristics.

Two research strategies have been used to document the impact of breast cancer upon psychological distress and QOL: cross-sectional research designs with the inclusion of comparison groups of individuals without malignancy [e.g., 3-5] and prospective, longitudinal research designs with or without the inclusion of non-malignant comparison groups [e.g., 6-11]. Each design has advantages and disadvantages. While a more powerful strategy for assessing the impact of breast cancer, the prospective, longitudinal design tends to focus upon QOL and psychological distress during the first year or two after breast cancer diagnosis [6-11]. In contrast, the cross-sectional design is well-suited to examining the long-term impact (e.g., > 1-2 years post diagnosis) of breast cancer because one does not need to wait the requisite number of years for a prospective cohort to mature [3]. On the negative side, inferences drawn from cross-sectional designs are dependent upon the type and quality of comparison groups included in the design.

At least two types of comparison groups are appropriate for assessing the impact of breast cancer: healthy women without a history of breast cancer and women with benign breast disease, such as benign cysts, a history

of benign breast biopsy, or fibrocystic breast disease [12-13]. Assessment of QOL and psychological distress in women with benign breast disease allows some estimate of the impact of the diagnosis and treatment of cancer over and above any impact attributable to the presence of non-malignant breast problems [cf., 14-15]. Only a few studies of psychological adjustment following breast cancer treatment have employed a benign breast disease comparison group [7-8, 11]. In all cases, this group was defined in terms of a history of a benign breast biopsy. In an initial study women two years post-mastectomy for breast cancer reported greater depression than women with benign breast disease [7]. No significant differences were found with regard to either marital or sexual adjustment or quality of interpersonal relationships. In a later study, women one-year post-mastectomy evidenced poorer status than women with benign breast disease on measures of psychosocial impairment, psychological and somatic distress, and physical complaints [8]. Finally, breast cancer patients 16 months post breast surgery reported greater psychological distress than women with benign breast disease [11]. In sum, results consistently suggest greater distress in women with breast cancer one to two years following breast surgery relative to women with benign breast disease.

The conclusions that can be drawn from research comparing psychological adjustment in breast cancer and benign breast disease groups can be limited by the failure to control for differences in age between these two groups. Benign breast problems decrease in frequency and severity following menopause [12-13] while breast cancer is most likely to be diagnosed postmenopausally. Thus age distributions of breast cancer and benign breast disease groups are non-overlapping to a degree in the general population.

Since age has been found to be inversely related to psychological distress in both breast cancer [10, 16-17] and community samples [18], studies that fail to control for age may actually underestimate differences in psychological distress between these groups. Of the three studies cited above [7-8, 11], only one controlled for age in the statistical analyses [8] and none controlled for age using matching procedures.

Most previous research assessing psychological adjustment and QOL following cancer diagnosis and treatment has also been limited by a failure to include measures of positive psychosocial adaptation. There is growing realization that the diagnosis and treatment of cancer is not a stressor with uniformly negative outcomes but rather a "transitional" event with the potential for positive as well as negative outcomes [19-20]. According to Parkes [20], transitional events are traumatic events, such as death of a spouse, job loss, criminal victimization, or confrontation with a life-threatening disease, which: (a) involve major life changes; (b) are lasting in their effects; and (c) alter the set of assumptions an individual previously held about the world. An earlier comparison of cancer patients and healthy controls found that cancer patients were more likely to report improvements in religious satisfaction, self-respect, and love for their spouse or partner [19]. Other studies have mirrored these results and have also suggested that cancer can be associated with improvements in outlook on life [21-24]. Assessment of psychological distress alone in comparisons of breast cancer and BBP groups may serve to underestimate the quality of psychosocial adjustment evidenced following treatment for breast cancer.

The present study is a cross-sectional comparison of current psychosocial adjustment and QOL in women with breast cancer and age-matched

women with benign breast problems. These two groups are compared with respect to measures of distress and general QOL as well as indices of positive adaptation. It is hypothesized that relative to age-matched women with benign breast problems, women with breast cancer will report: (1) poorer physical health and functioning; (2) greater psychological distress; and (3) more positive psychosocial adaptation, such as improved life outlook, self-respect, religious satisfaction and intimate relationships.

Methods and Materials

Subjects

To be eligible for the Breast Cancer (BC) group a woman had to: (1) be at least 18 years of age; (2) have a first-time diagnosis of Stage I, II, or IIIA carcinoma of the breast [25]; (3) be 3 to 60 months post-completion of all primary cancer treatment, including surgery, radiotherapy, and chemotherapy; (4) be currently in remission and have no history of recurrent disease following initial breast cancer treatment; (5) read, write, and understand English; and (6) provide written consent for participation. To be eligible for the Benign Breast Problem (BBP) group a woman had to: (1) be at least 18 years of age; (2) have no prior history of breast cancer; (3) have a history of fine needle aspiration biopsy of the breast or excisional breast biopsy for benign disease and/or have a previous diagnosis of fibrocystic breast disease and be receiving routine care and cancer screening for this condition consisting of mammography in conjunction with a clinical breast examination; (4) be age-matched (within 4 years) with a woman enrolled in the BC group; (5) read, write, and understand English; and (6) provide written consent for participation.

Procedure

Consecutive series of women eligible for inclusion in either the BC or BBP groups were identified from the daily roster of patients seen at the University of Kentucky Comprehensive Breast Care Center. An eligible woman was introduced to the study by the physician managing her care. If interested, further information about the study was provided by a doctoral level research assistant. Written informed consent for participation was then obtained. The woman was given a packet of questionnaires to complete and return by mail. The mean number of days between study entry and questionnaire return were 15.8 and 14.6 days for the BC and BBP groups, respectively. Disease and treatment information was abstracted from medical records. All women received \$10.00 following completion of their questionnaire packet. Less than 5% of women eligible for the BC or BBP groups refused to participate in the study. Among study enrollees, failure to return a completed questionnaire packet was 14% for the BC group and 20% for the BBP group.

Self-Report Measures

A number of standardized questionnaires were employed. These were supplemented by several instruments or individual items used in our previous research or developed specifically for use in the present research.

The Medical Outcome Studies Short-Form general Health Survey (MOS-36) is a 36-item health status measure for use with healthy and medical populations [26]. Eight separate subscale scores are computed: physical and social functioning, role limitations due to physical health problems, role limitations due to emotional problems, bodily pain, vitality, mental health, and general health perceptions. Subscale scores range from 0 to 100

with higher scores indicating more favorable health states.

The Center for Epidemiological Studies Depression Scale (CES-D) is a 20 item measure of depressive symptomatology [27]. The CES-D avoids the physical health bias present in many scales for measuring depression and thus is well-suited to measuring depressive symptomatology in medically ill populations. Scores range from 0 to 60 with higher scores indicative of greater depressive symptomatology.

The Profile of Mood States (POMS) is a 65 item measure of recent affective state [28]. A Total Mood Disturbance score (POMS-TMD) is computed along with subscale scores for Depression (D), Tension (T), Anger (A), Fatigue (F), Vigor (V), and Confusion (C). Higher scores indicate poorer mood status except for the Vigor subscale.

The Positive and Negative Affect Scale (PANAS) is a 20 item measure of current mood [29]. The PANAS yields subscale scores for positive and negative affect. Higher subscale scores indicate greater positive or negative affect.

The Cancer Patient Behavior Scale (CPBS) is a 24 item measure of positive and negative attitudinal, behavioral, and interpersonal change following the diagnosis of cancer [30]. For each item, respondents rate their current status relative to their status prior to their cancer diagnosis. Ratings are made on a five point scale ranging from -2 to +2 with anchor points "much worse than before my cancer" to "much better than before my cancer." The midpoint ("0") indicates current status is the same as prior to cancer diagnosis.

The Perceived Health Questionnaire (PHQ) assesses perceptions of general physical health and global QOL [19, 31]. The PHQ utilizes a 10-

step, health ladder technique [32] to obtain separate ratings from respondents of current physical health, the health of a typical person their age, and their own health prior to cancer diagnosis. Similar ratings are obtained for current global QOL, QOL of a typical person their age, and QOL prior to cancer diagnosis.

Finally, respondents' perceptions regarding the current importance of spiritual concerns was assessed with a single item (SPIRITUAL-Import). A 7-point Likert scale anchored at the lower end by "not important at all" and at the higher end by "extremely important," was employed.

Because the CPBS and PHQ require respondents to evaluate their current status relative to their status prior to cancer diagnosis, modifications were necessary for use by the BBP group. Similar to our previous use of the CPBS with a healthy comparison group [19], BBP respondents evaluated their current status relative to a specified prior point in time. This point in time was determined by the number of months between cancer diagnosis and study participation for their age-matched counterpart in the BC group. For example, if a member of the BBP group was matched with a BC patient who was 15 months post-diagnosis at time of study participation, the BBP respondent was asked to evaluate their current status relative to their status 15 months previous. Thus, respondents in both the BC and BBP groups completed the PHQ and CPBS with respect to similar temporal frames of reference.

Data Analysis

Standard procedures were used to compute scale and subscale scores on the MOS-36, CES-D, and PANAS. POMS-Mood Disturbance scores were computed using the formula $T+D+A+F+C+(32-V)$ [19, 31]. For each scale, subscale, or item score, mean substitution was used to supply values for missing data

only if less than 5% of values were missing for that measure.

Specific dependent variables used in the analyses of differences in QOL between the BC and BBP groups were selected to reflect a multidimensional view of QOL as consisting of physical, psychological, social, and spiritual dimensions [33]. Specific dependent variables were also selected to include potential measures of positive psychosocial adaptation such as positive affect or improvements in life outlook, self respect, and intimate relationships. Based upon these twin considerations, a core set of 13 QOL indices was selected and served as the focus of our analyses. Indices assessing the physical dimension of QOL included the Physical Functioning subscale from the MOS-36 (MOS-Physical) and the rating of current physical health from the PHQ (PHQ-Health). Indices assessing the psychological dimension of QOL included the total mood disturbance score from the POMS (POMS-Mood Disturbance); the total depressive symptom score from the CES-D (CES-Depression), the positive affect subscale score from the PANAS (PANAS-Positive Affect), and individual CPBS items for "life outlook" (CPBS-LIFE Outlook) and "self respect" (CPBS-Self Respect). Indices assessing the social dimension of QOL included the Social Functioning subscale from the MOS-36 (MOS-Social), and individual CPBS items for "relationship with spouse/partner" (CPBS-Spouse Relation) and "love for spouse/partner" (CPBS-Spouse Love). Indices assessing the spiritual dimension of QOL included the single item assessing importance of spiritual concerns (SPIRITUAL-Import) and the CPBS item "satisfaction with religion" (CPBS-Rel. Satisfaction). Finally, global QOL was indexed using the current QOL rating from the PHQ (PHQ-Current QOL).

Data were analyzed using the Statistical Package for the Social

Sciences - X (SPSS-X). All analyses utilized the entire BC and BBP groups unless otherwise indicated. An alpha value of .05 was used as the criterion for statistical significance. No correction for multiple statistical analyses was employed for two reasons: (a) only a relatively small number of between groups (17) and within groups (8) analyses of QOL differences for the BC and BBP groups were conducted; and (b) between groups analyses were based upon specific a priori hypotheses.

Results

Patient Selection

Subjects in the BC group ($n=80$) were a mean of 53.9 years of age ($SD=9.3$; range 35-76 years) and a mean of 28.2 months post-diagnosis of breast cancer ($SD=15.1$; range 6-57 months). Women had completed primary breast cancer treatment a mean of 24.6 months prior to study participation ($SD=15.3$; range 3-54 months). Pathologic staging at diagnosis varied in the BC group with all women having either Stage I ($n=45$), II ($n=29$), or IIIA ($n=6$) carcinoma of the breast. Primary breast cancer treatment also varied. All women underwent lumpectomy ($n=22$), modified radical mastectomy ($n=57$), or radical mastectomy ($n=1$). A majority of women received adjuvant therapy in addition to surgery including chemotherapy ($n=26$), radiotherapy ($n=23$), or chemotherapy in combination with radiotherapy ($n=8$). Tamoxifen was prescribed as adjuvant hormonal therapy for 35 women (44%) in the BC group at the time of study participation. Finally, 16 women (20%) had undergone breast reconstruction subsequent to breast surgery.

Subjects in the BBP group ($n=80$) were a mean of 53.3 years of age ($SD=8.7$; range 37-76 years). One-third (27/80) had a history of excisional

breast biopsy. Income, marital status, race, whether minor children were in the home, and education for both the BC and BBP groups are shown in Table 1.

As shown in Table 1, chi-square comparison of the BC and BBP groups with regard to demographic variables, specifically education, income, marital status, race, and whether children lived in the home, revealed a only a marginally significant difference between these groups for marital status ($\chi^2(1)=2.69$; $p \leq .10$). Marital status (unmarried vs. married) was therefore used as a covariate in all analyses of covariance (ANCOVA).

QOL: Differences Between BC and BBP Groups

QOL: Physical Dimension. Differences between the BC and BBP groups with regard to physical health and functioning were examined using separate ANCOVA for each of two QOL indices: MOS-Physical and PHQ-Current Health. As shown in Table 2, the BC group reported significantly poorer status with regard to both PHQ-Current Health ($F(1, 157)=5.42$; $p < .05$) and MOS-Physical ($F(1, 157)=7.38$; $p < .01$) scores.

Two additional "between groups" analyses using ANCOVA with marital status as covariate revealed no differences between the BC and BBP groups with regard to PHQ ratings of physical health of a typical person their age ($F(1,157)=3.02$; n.s.) or their own previous physical health ($F(1,157) = 1.35$; n.s.). (See Table 3). However, "within groups" analyses using paired t-test indicated that the BC group rated their current physical health as poorer than both the health of a typical person their age ($t(79)=2.10$; $p < .05$) and poorer than their own previous health ($t(79)=4.28$; $p < .001$). In contrast, the BBP group rated their current physical health significantly better than the health of a typical person their age ($t(79)=2.45$; $p < .05$) but not different from their previous health ($t(79) = .30$; n.s.).

QOL: Psychological Dimension. Differences between the BC and BBP groups with regard to psychological distress and adaptation were examined using separate ANCOVA's for each of 5 QOL indices: CPBS-Life Outlook, CPBS-Self Respect, CES-Depression, PANAS-Positive Affect, and POMS-Mood Disturbance. As shown in Table 2, the BC and BBP groups differed significantly only with regard to CPBS-Life Outlook ($F(1, 157)=11.82$; $p \leq .001$). Women in the BC group reported greater recent improvement in their "outlook on life" relative to the BBP group.

QOL: Social Dimension. Differences between the BC and BBP groups with regard to social and interpersonal functioning were examined using separate analyses for each of 3 indices: MOS-Social, CPBS-Spouse Love, and CPBS-Spouse Relation. Results are shown in Table 2. ANCOVA analysis of MOS-Social scores revealed no difference between the BC and BBP groups. Twenty-nine women (18%) did not have a spouse or partner and thus were missing data on the CPBS-Spouse Love and CPBS-Spouse Relation indices. Thus differences between the BC ($n=62$) and BBP ($n=69$) groups for these two variables were analyzed using ANOVA. Women in the BC group reported significantly greater improvement in their love for their spouse/partner relative to the BBP group ($F(1,128)=14.29$; $p < .001$). Similarly, women in the BC group also reported greater improvement in their relationship with their spouse/partner but these results narrowly missed meeting our .05 criterion for statistical significance ($F(1,128)=3.31$; $p=.07$).

QOL: Spiritual Dimension. Differences between the BC and BBP groups with regard to the Spiritual dimension of QOL were examined using separate ANCOVA's for each of 2 QOL indices: CPBS-Rel. Satisfaction and SPIRITUAL-Importance. As shown in Table 2, results indicated that the BC group

reported significantly greater recent improvement in religious satisfaction ($F(1, 157)=8.99$; $p < .01$) and ascribed significantly more importance to spiritual concerns ($F(1,157) = 4.15$; $p < .05$).

QOL: Global Ratings. Finally, differences between the BC and BBP groups with regard to ratings of current global QOL were examined using ANCOVA with PHQ-Current QOL ratings as dependent variable. As shown in Table 2, results indicated no significant difference between the BC and BBP groups ($F(1, 157)=1.40$; n.s.) with regard to global ratings of current QOL.

While the BC and BBP groups did not differ with respect to PHQ ratings of current global QOL, inspection of the pattern of QOL ratings on the PHQ revealed clear differences between these two groups (see Table 3). "Between groups" analyses using ANCOVA with marital status as covariate revealed a significant difference between the BC and BBP groups for PHQ ratings of QOL of a typical woman their age ($F(1, 157)=9.71$; $p < .01$). Specifically, the BC group viewed a typical woman their age as having better QOL than did women in the BBP group. No differences were obtained between these groups for ratings of their own previous QOL ($F(1, 157)=1.38$; n.s.). Furthermore, "within groups" analyses using paired t-test revealed no differences between ratings of current QOL and either QOL of a typical person their age ($t(79)=.21$; n.s.) or previous QOL ($t(79)=1.44$; n.s.) for the BC group. In contrast, the BBP group rated their current QOL significantly higher than the QOL of a typical person their age (paired- $t(79)=4.97$; $p < .001$) and higher than their own previous QOL (paired- $t(79)=2.94$; $p < .01$).

QOL: Association with Disease and Treatment Variables

The association between the QOL reported by women in the BC group and various disease and treatment variables was examined using univariate

correlational analyses. As appropriate, Pearson Product or Point Biserial correlations were computed between each of our 13 core QOL indices and a set of 6 disease (stage at diagnosis) and treatment (type of surgery, current tamoxifen usage, time since completion of primary BC treatment, breast reconstruction, and type of adjuvant therapy received) variables. The matrix of correlations is shown in Table 4. QOL was largely unrelated to the disease and treatment variables examined. Only 5 of the 78 correlations (6%) computed met the .05 criterion for statistical significance.

Discussion

Consistent with our hypothesis, women with breast cancer reported decrements in physical health and functioning long after conclusion of primary cancer treatment. This was demonstrated in two ways. First, "between groups" analyses indicated that the BC group reported poorer physical health and functioning than the BBP group (Table 2). Second, "within groups" analyses indicated that the BC group rated their own current physical health as poorer than their own health prior to cancer diagnosis and poorer than the health of a typical person their age (Table 3). In contrast, the BBP group rated their current physical health as no different from their own prior health and better than the physical health of a typical person their age. The presence of decrements in physical health and functioning after breast cancer treatment is not surprising given the well-known, physical impact of cancer treatment [34-35]. However, the existence of such decrements long after the conclusion of primary breast cancer treatment has not been well-demonstrated by previous research. Our data are sobering and suggest that opportunities for physical rehabilitation may

continue long after conclusion of breast cancer treatment.

The BC and BBP groups did not significantly differ with regard to psychological distress. This finding contrasts with both our hypothesis as well as prior research suggesting greater psychological distress in women with breast cancer relative to women with benign breast disease [7, 8, 11]. Differences between the present and previous studies with regard to case mix or timing of assessment of psychological distress could have accounted for the different results. Notably, the present study included women up to 55 months posttreatment for breast cancer whereas the studies cited above included only women up to two years postsurgery. Time posttreatment, however, was not associated with any of our QOL indices (Table 4), making this an unlikely explanation for differences between present and previous findings. Alternatively, earlier comparisons of breast cancer and benign breast disease groups focused upon adjustment following mastectomy. Only one study [11] included both lumpectomy and mastectomy patients, as did the present study. If mastectomy is associated with greater distress, this could account for our failure to replicate previous findings of greater distress in women with breast cancer [7-8]. Again, however, we found no differences between mastectomy and lumpectomy patients with regard to any of our measures of QOL (Table 4).

In light of the inadequacy of these methodological explanations, we cautiously suggest that our failure to replicate previous findings of greater distress following breast cancer might be attributable to historical changes in the social and health care milieu within which breast cancer occurs. Recent advances in treatment and supportive care, along with increasing public awareness of breast cancer, may have created a current

climate which reduces the distress previously associated with the disease and/or promotes the experience of positive psychosocial adaptation.

While no differences were found between the BC and BBP groups with regard to psychological distress, these groups did differ with regard to measures of positive psychosocial adaptation. The BC group was more likely to report improvements in outlook on life, spouse/partner relationships, and satisfaction with religion, and to ascribe more importance to spiritual concerns. These findings are consistent both with our hypothesis and previous research documenting positive psychosocial sequelae following cancer diagnosis and treatment [19, 21-24]. Coupled with our failure to find differences in psychological distress between the BC and BBP groups, evidence of greater positive psychosocial adaptation in the BC group suggests that long-term psychological adjustment in women with breast cancer might be superior to women with benign breast problems.

Our finding of equal, if not superior, psychosocial adaptation in the BC group relative to their BBP counterparts is remarkable for two reasons. First, the possibility of disease recurrence exists for women in the BC group. Thus, reports of an improved "outlook on life" suggest that many women are able to look beyond this obvious concern and experience a renewed sense of life purpose, greater appreciation of the moment, and an ability to view life's daily stresses in a more favorable context. Second, in light of the oft-established inverse relationship between physical health and functioning and psychological distress [e.g., 36-38], one might anticipate that the BC group would report greater distress relative to the BBP group. However, similar to previous research comparing cancer patients and healthy controls [19], quite dissimilar physical status was associated with quite

similar status with regard to psychological distress.

What might account for this seeming anomaly? At least several hypotheses can be advanced. First, the experience of breast cancer might alter internal reference points which mediate perceptions of current physical and psychosocial status [39] and which are critical to an individual's evaluation of their QOL. The fact that the BC group rated the QOL of a typical woman their age significantly higher than did the BBP group (see Table 3) suggests that some alteration of reference points might occur following breast cancer. Second, as time passes, any physical or functional deficits associated with breast cancer treatment might be evaluated less threateningly. To some degree, women may adjust to the presence of such deficits and compensate by placing less importance upon this QOL dimension [40]. This could weaken the typically strong relationship between physical health and functioning and psychological distress. Third, positive psychosocial sequelae triggered by the cancer experience could counterbalance any psychological distress associated with decrements in physical health or functioning. This would result in little net difference between the BC and BBP groups on distress indices.

While our results are provocative, caution in their interpretation is warranted for several reasons. First, while statistically significant differences between the BC and BBP groups were evident on a number of measures of physical and psychosocial status, the clinical significance of these differences is difficult to gauge. Table 2 indicates that the effect size for measures that differentiated the BC and BBP groups ranged from a quarter to a half of a standard deviation. While this is viewed as a "medium" sized effect [41], the question of how different the BC and BBP

groups "really" are remains unanswered. Second, we assessed women a mean of 28 months post-diagnosis of breast cancer and found no differences in distress relative to the BBP group. Had we assessed distress in the BC group earlier in the course of their disease when women have had less time to cope and adapt, we might have indeed found differences in distress. Finally, use of a BBP comparison group allowed us to assess the impact of breast cancer upon QOL and psychological adjustment beyond any impact potentially due to a history or presence of benign breast disease. It must be emphasized, however, that a BBP comparison group is not the same as a comparison group of healthy women. Some benign breast problems, for example, a history of excisional breast biopsy, are risk factors for future breast cancer. Thus while the breast cancer and BBP groups did not differ on measures of psychological distress in our study, both groups might be more distressed than healthy women. Unfortunately, we did not include a second comparison group of age-matched healthy women in our design due to limited resources. However, inclusion of a healthy comparison group in future research would strengthen any conclusions to be drawn regarding the impact of breast cancer upon long-term QOL and psychosocial adjustment.

In conclusion, our data suggest that while deficits in physical health and functioning might linger long after the completion of primary breast cancer treatment, the long-term psychosocial adjustment of women with breast cancer is no worse than, and may even be superior to, that of age-matched women with benign breast problems. Any superiority enjoyed by women with breast cancer is likely due to the occurrence of positive psychosocial sequelae, such as enhanced outlook on life, improved intimate relationships, or deeper religious and spiritual satisfaction, triggered by the experience

of cancer. Our results have clear clinical, theoretical, and methodological implications. Clinically, our finding that women with breast cancer continued to report poorer physical health and functioning long after conclusion of primary breast cancer treatment suggests that increased attention be paid to physical rehabilitation needs of long term breast cancer survivors. Theoretically, our results support the conceptualization of cancer as a "transitional" event with the potential for enhanced psychosocial adjustment [19-20]. Methodologically, our results underscore the importance of including measures of both psychological distress and when assessing psychosocial adjustment following "transitional" events such as breast cancer. Failure to assess the presence of positive psychosocial adaptation may yield an incomplete and potentially misleading picture of psychosocial adjustment following cancer diagnosis and treatment.

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Table 1

Demographic Characteristics for Breast Cancer and Benign Breast Problem Groups.

VARIABLE	BREAST CANCER (<u>n</u> =80)	BENIGN BREAST PROBLEMS (<u>n</u> =80)	χ^2 ^a	p ^b
Married	56%	70%	2.69	.10
Income			6.48	.17
< \$15K	33%	17%		
\$15K - \$30K	19%	22%		
\$30K - \$50K	14%	14%		
\$50K - \$80K	17%	27%		
> \$80K	17%	20%		
Education			4.84	.18
not completed high school	23%	19%		
completed high school	25%	16%		
some college/college degree	22%	38%		
> college degree ^c	30%	28%		
Minor Children in Home	28%	20%	0.86	.35
Caucasian	91%	95%	0.39	.53

^a Chi-square test of difference between Breast Cancer and Benign Breast Problem Groups. Yates correction used for 2 X 2 analyses.

^b p-value associated with chi-square test

^c at least one post-baccalaureate course or a post-baccalaureate degree

Table 2

Means and Standard Deviations for QOL Indices for Breast Cancer (BC) and Benign Breast Problem (BBP) Groups.

	BREAST CANCER (<u>n</u> =80)	BENIGN BREAST PROBLEMS (<u>n</u> =80)		
QOL DIMENSION/VARIABLE	MEAN	MEAN	SD ^a	<u>F</u> ^b
PHYSICAL DIMENSION				
MOS-Physical	70.7	81.2	25.9	7.38 **
PHQ-Current Health	7.1	7.8	1.9	5.42 *
PSYCHOLOGICAL DIMENSION				
CPBS-Life Outlook	0.7	0.2	1.0	11.82 ***
CPBS-Self Respect	0.6	0.3	0.9	2.83
CES-Depression	11.3	9.4	10.5	1.38
POMS-Total Mood Disturbance	51.8	47.7	38.5	.45
PANAS-Positive Affect	33.6	34.4	8.5	.39
SOCIAL/INTERPERSONAL DIMENSION				
CPBS-Spouse Love	0.7	0.2	1.0	14.29 ***
CPBS-Spouse Relation	0.5	0.2	1.0	3.31
MOS-Social	81.8	85.3	23.6	.86
SPIRITUAL DIMENSION				
CPBS-Rel. Satisfaction	0.7	0.3	0.9	8.99 **
SPIRITUAL-Importance	6.1	5.7	1.7	4.15 *
GLOBAL QOL RATING				
PHQ-Current QOL	7.8	8.2	2.0	1.40

Note. Means shown are adjusted for the covariate marital status (married vs. unmarried) for all dependent variables except for CPBS-Spouse Love and CPBS-Spouse Relation.

^a Standard deviation in combined sample ($\underline{n} = 160$)

^b $\underline{F}$ -value for test of difference between BC and BBP groups.

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 3

Means and Standard Deviations For PHQ Ratings of Health and QOL For Women
With Breast Cancer and Benign Breast Problems.

VARIABLE	BREAST CANCER (n=80)		BENIGN BREAST PROBLEMS (n=80)		F^a
	MEAN	SD	MEAN	SD	
Current Health	7.1	2.0	7.8	1.7	5.42 *
Health of Typical Woman	7.6	1.6	7.2	1.5	3.02
Previous Health ^b	8.1	1.7	7.9	2.1	1.35
Current QOL	7.8	2.2	8.3	1.7	1.40
QOL of Typical Woman	7.8	1.5	7.1	1.4	9.71 **
Previous QOL ^b	8.2	1.8	7.9	2.1	1.38

^a F -value for ANCOVA test of difference between Breast Cancer and Benign Breast Problem groups.

^b Prior to cancer diagnosis for Breast Cancer group; prior to designated previous point in time for Benign Breast Problem group.

* $p < .05$; ** $p < .01$

Table 4

Correlations Between QOL Indices and Disease/Treatment Variables for BC Group.

QOL INDEX	DISEASE/TREATMENT VARIABLE ^a					
	BREAST RECONSTRUCTION	TYPE OF SURGERY	CURRENT TAMOXIFEN	TIME POST-TX	ADJUVANT THERAPY	DISEASE STAGING
PHYSICAL DIMENSION						
MOS-Physical	.07	.04	.40**	-.02	-.04	-.13
PHQ-Current Health	.18	.12	.07	.09	-.10	-.10
PSYCHOLOGICAL DIMENSION						
CPBS-Life Outlook	.04	-.02	.09	.14	-.15	-.06
CPBS-Self Respect	-.02	-.14	.11	.05	-.04	.03
CES-Depression	-.02	.02	-.16	-.06	.01	.22*
POMS-Mood Disturbance	-.07	-.08	-.08	-.06	.03	.13
PANAS-Positive Affect	.10	.03	.05	.21	-.17	-.06
SOCIAL DIMENSION						
CPBS-Spouse Love	.13	-.14	-.11	.05	-.14	.36**
CPBS-Spouse Relation	.02	-.15	.05	-.06	-.21	.22
MOS-Social	.05	.04	.21	.01	-.06	-.13
SPIRITUAL DIMENSION						
CPBS-Rel. Satisfaction	.01	-.12	-.25*	.04	-.05	.21
SPIRITUAL-Importance	-.17	-.03	-.23*	.02	.02	.14
GLOBAL QOL RATING						
PHQ-Current QOL	.06	.14	.08	.09	-.02	-.03

^a Coded as: Breast Reconstruction, Current Tamoxifen (0=no; 1=yes); Type of Surgery (0=lumpectomy; 1=partial or radical mastectomy); Adjuvant Therapy (0=no adjuvant chemotherapy or radiotherapy; 1=adjuvant chemotherapy or radiotherapy; 2=adjuvant chemotherapy and radiotherapy); Disease Staging (1=Stage I; 2=Stage II; 3=Stage IIIA).

Note. Pearson product moment correlations computed for Time Post-TX, Disease Staging, and Adjuvant Therapy. Point biserial correlations computed for Breast Reconstruction, Type of Surgery, and Tamoxifen.

* $p < .05$; ** $p < .01$

Interest in Learning of Personal Genetic Risk For Cancer:

A General Population Survey

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RUNNING HEAD: GENETIC TESTING FOR CANCER

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Abstract

BACKGROUND: Previous studies have reported high interest in genetic testing for risk for colon or breast/ovarian cancer. These studies, however, have used samples which might be atypical with regard to level of interest evident in the general U.S. population.

METHODS: As part of an annual statewide telephone health survey, adults' ($n=649$) interest in learning about their personal genetic predisposition for cancer was assessed.

RESULTS: High levels of interest in learning about a personal genetic predisposition for cancer in general (87%) and breast cancer in particular (93%) were expressed. Logistic regression analysis indicated that lack of interest was associated with less education, minority status, and less performance of other health protective behaviors. Only 53% of respondents reported their understanding of genetics was "good" or "excellent."

CONCLUSION: While interest in learning of one's personal genetic predisposition for cancer was high, many individuals requesting testing may have a less than good understanding of genetics and the implications of test results. Furthermore, variables associated with lack of interest in learning about personal genetic risk for cancer in this study were similar to those which have been previously found to be associated with poor utilization of other cancer control activities such as breast or cervical cancer screening.

Interest in Learning of Personal Genetic Risk for Cancer:

A General Population Survey

As the genetic basis for familial cancer syndromes becomes better understood, interest in presymptomatic, predictive testing for a variety of inherited cancer syndromes has developed [1-2]. Of particular interest is the role of genetic inheritance in susceptibility for breast and ovarian cancers. Geneticists have identified a gene on chromosome 17, specifically 17q21, that is the cause of approximately 5% of all breast cancers [3-5]. This gene, known as BRCA1, is inherited through an autosomal dominant pattern akin to the pattern of transmission of Huntington's disease [4-6]. However, unlike the gene that causes Huntington's disease, BRCA1 is not 100% penetrant. In other words, a carrier of a BRCA1 mutation will not necessarily develop breast or ovarian cancer. However, BRCA1 mutation carriers are at approximately an 85% risk of developing breast cancer during their lifetime [7]. This risk exceeds the 12-13% lifetime risk of developing breast cancer in the general population [8].

At the present time, predictive testing for BRCA1 gene mutations is largely limited to research settings [5]). While testing for BRCA1 should be available to the general public in clinical settings in the near future [1], research exploring interest in predictive testing for a genetic predisposition for breast and ovarian cancer, as well as other cancers, is limited. Croyle and Lerman [9] examined interest in genetic testing for colon cancer susceptibility in a statewide telephone survey of 401 adults in Utah. Results indicated that 83% of their sample were at least "somewhat" interested in having a blood test to assess their genetic risk for colon cancer. Perceived personal risk for colon cancer was the best predictor of interest in genetic testing for colon cancer. Concern about developing cancer, ratings of nervousness/upset during

the past year, and demographic variables such as age, education, income, and gender were not associated with interest in genetic testing for colon cancer.

Lerman et al. [10] assessed interest in genetic testing for breast and ovarian cancer among women with at least one first degree relative with ovarian cancer. Seventy-five percent of 121 respondents reported that they "definitely" desired testing for BRCA1 mutations. An additional 20% of respondents stated that they would "probably" be interested in such testing. Interest in genetic testing was positively associated with age, education, psychological distress (i.e., total mood disturbance scores on the Profile of Mood States), perceived likelihood of being a gene carrier, and perceived risk for ovarian cancer. In a similar study [11] interest in genetic testing for breast/ovarian cancer risk was assessed in 105 first degree female relatives of women with breast cancer. Ninety-five percent of respondents stated they would want to be tested.

The results of these three studies suggest that interest in testing for a personal genetic predisposition for cancer is high. However, the level of interest in genetic testing found in these two studies may significantly overestimate interest in the general population. Croyle and Lerman [9] acknowledged that while respondents in their study were representative of Utah residents, it was likely that their sample was critically unrepresentative of residents of the United States as a whole. Specifically, most survey respondents were members of the Church of Jesus Christ of Latter Day Saints, a religious group known for its interest in genealogy. Similarly, women with a first degree relative with breast or ovarian cancer are likely to have a heightened awareness of their personal cancer risk relative to the general population. Therefore, respondents in the studies by Lerman et al. study [9-10] may have evinced greater interest in genetic testing for cancer risk.

We report the results of a statewide telephone survey of adults' interest in learning about a personal genetic predisposition for cancer. The primary purpose of our investigation was to identify the level of interest in testing for genetic susceptibility to cancer in a sample of adults reasonably representative of the United States population. Secondly, we hoped to identify variables, such as sociodemographic factors, emotional status, access to health care, or performance of other potentially health protective behaviors, that might be associated with interest in learning of a personal genetic predisposition for cancer. Based upon previous research in this area, we hypothesized that interest in learning of a personal genetic predisposition for cancer would be positively associated with education, age, and poorer emotional status [10]. In addition, assuming that knowledge of genetic risk status for cancer is most likely to be helpful to individuals who are most capable of taking steps which might reduce their cancer risk, we hypothesized that better access to health care would be positively associated with interest in learning of one's personal genetic risk status. Finally, we hypothesized that interest in learning of personal genetic cancer risk status would be associated with performance of other health protective behaviors. We based this hypothesis upon both empirical as well as theoretical considerations. First prior research suggests that potentially health protective behaviors, such as seeking out genetic risk information, often cluster together [12]. Second, some formulations of the Health Belief Model posit that performance of health protective behaviors is associated with general health motivation, that is, a general interest or concern about health [13-15]. Performance of a variety of health protective behaviors is presumedly indicative of general health motivation.

Methods

Procedure

Study data were obtained from telephone interviews completed during June and July of 1994 as part of an annual health-related survey of Kentucky residents. The survey was conducted by the Survey Research Center at the University of Kentucky. The Survey Research Center, established in 1979, is a University-based center whose faculty and staff have broad-based expertise in survey design and administration, and who have extensive experience in state-wide, regional, and national surveys for University faculty, state government and federal agencies such as the Centers for Disease Control. The telephone survey protocol used computer-assisted telephone interviewing. Quality control procedures included telephone monitoring, supervisor follow-up verification, post-interview coding and editing, and consistency check analysis of all final data files. The questions specific to this project were included as part of the annual Kentucky Health Poll. Each residential telephone line in Kentucky had an equal probability of being called by the random-digit dialing procedure. In addition to standard screening approaches, every person was specifically asked whether the line being called was a residential telephone line. The trained interviewers questioned the first respondent over 18 years of age in the household.

A total of 1326 residential telephone numbers were called. Refusals to participate or incomplete interviews resulted from 534 calls while 143 respondents were ineligible (e.g., deaf, too ill, unavailable after repeated calls at different times of day, etc.). A total of 649 calls resulted in complete telephone interviews. This constituted 55% of telephone calls to eligible households (649 of 1183).

Survey Questions

Responses to four clusters of interview questions are examined in this report. These included (in order of inclusion in the survey): protective health behaviors, current affective status, health care system access and utilization, and genetics and cancer. Questions regarding general health perceptions and health-related quality of life preceded the cluster of questions regarding genetics and cancer but were not examined in this report.

Genetics and Cancer. Five questions were used. A single question assessed respondents' concern that they will develop cancer in their lifetime. Responses were made on a four point Likert scale ranging from "very concerned" to "not at all concerned." Two questions assessed respondents' interest in being informed if they possessed a genetic predisposition to develop cancer. The first question was "Suppose you had inherited something from your parents which would make you more likely to develop cancer than most people, would you want to be told this or not?" Respondents answered yes or no. A parallel question was asked of female respondents and was "Suppose you had inherited something from your parents which would make you more likely to develop breast cancer than most women, would you want to be told this or not?" Respondents' self-assessment of their understanding of genetics was assessed by the question "How would you rate your understanding of how people inherit characteristics like eye color or hair color?" Responses were made on a four point Likert scale ranging from "poor" to "excellent." The last question in this cluster examined respondents' beliefs regarding the importance of maternal and paternal family history in understanding breast cancer risk. Respondents were asked "Is the likelihood that a woman will develop breast cancer most affected by the history of breast cancer in her mother's family, her father's family, or her mother's

and father's family equally?

Protective Health Behaviors. Four questions assessed respondent's performance of protective health behaviors. Questions asked of all respondents included: (1) How often do you go to the dentist? (response alternatives included: more frequently than every six months, every six months, every 12 months, every 2-3 years, as need arises, not at all); (2) How often do you wear a seat belt when driving or riding in a car? (response alternatives included: always, nearly always, sometimes, seldom, or never) and (3) Do you smoke cigarettes now? Responses to these three questions were classified as either health protective or not. Emphasis was placed upon differentiating individuals who were clearly exhibiting poor health protective behavior from those exhibiting more appropriate behaviors. Specifically, reports of "no" current smoking of cigarettes were classified as health protective. Responses to the dental visitation question that indicated regular dental visits (i.e., every 2-3 years or more frequently vs. "only when need arises" or "not at all") were classified as "health protective." Finally, responses to the seat belt usage question that indicated regular use ("always" or "nearly always" as opposed to "sometimes," "seldom," or "never") were classified as health protective. A composite protective HEALTH BEHAVIOR index was computed for each respondent by summing the number of "health protective" behaviors reported. HEALTH BEHAVIOR scores thus ranged from 0 to 3.

In addition, women were asked "Have you ever had a mammogram?" If yes, information regarding the time of their most recent mammogram was obtained (response alternatives included: within past year, 1 year, 2 years, 3-4 years, more than five years ago). Responses to the mammography question were classified as either appropriate or inappropriate according to American Cancer

Society guidelines for mammography screening [16]. Women between the ages of 40 and 49 were "appropriate" if they had received a mammogram within the past 2 years. Women age 50 and above were appropriate if they had received a mammogram within the past year. Since no ACS guidelines exist for women under age 40, mammography screening behavior of these women could not be labeled as appropriate or inappropriate. Hence, women under age 40 were excluded from analyses involving the mammography screening variable.

Health Care System Access and Utilization. Four questions assessed respondents' health care system access and utilization. Three questions required yes or no responses: (1) Do you have a doctor whom you can consult whenever you have medical problems or questions? (2) Are you presently covered by private medical insurance? and (3) Are you presently covered by either Medicaid or Medicare? Respondents also rated their difficulty in getting to an appropriate medical facility when necessary using a four-point Likert scale with response alternatives ranging from "very easy" to "very difficult."

Affective Status. Current affective status was assessed using the five-item Mental Health subscale from the 20-item Medical Outcome Study Short Form Health Survey (MOS-20 [17]). All five questions were six-point Likert-type scales with responses ranging from "all of the time" to "none of the time." Respondents answer each question with regard to their status during the past month. Higher scores indicate poorer mental health. Internal consistency, as indexed by coefficient alpha, was .87 for the Mental Health subscale.

Data Analysis

Data were analyzed using the Statistical Program for the Social Sciences - X (SPSS-X). All 2 X 2 chi square analyses employed Yates correction. An alpha level of .05 was used as the criterion for statistical significance.

Results

Sample Characteristics

The 649 respondents (45% male, 55% female) were a mean of 47.1 years of age (SD=16.5; range=18-88). The sample was primarily Caucasian (93%), with African-American respondents comprising an additional 6% of the sample. Educational status was: grade school (8%), some high school (12%), high school graduate (35%), some college (24%), college degree (10%), post-baccalaureate study or degree (11%). Marital status was: married (62%), never married (14%), separated, divorced, or widowed (24%). Finally, 27% of respondents lived in rural areas while 39% lived in small towns, and 34% lived in urban or suburban areas. The most common religious affiliations were: Baptist (37%), Roman Catholic (16%), and Methodist (8%). Members of the Church of Jesus Christ of Latter Day Saints consisted of less than 1% of the sample.

Comparison of study respondents with 1990 U.S. Census data [18] indicates the sample was representative of Kentucky residents as a whole with regard to proportion of minority respondents (7% in our sample vs. 8% in state as whole). Regarding educational attainment, the proportion of study respondents with high school degrees (80%) or four year college degrees (21%) exceeded the proportions in the state as a whole (65% and 14%, respectively).

Knowledge and Understanding of Genetics

Self-reported understanding of genetics varied across respondents (see Table 1). While 8% of respondents stated their understanding of genetics was "poor," 34% stated it was "average," 31% stated it was "good," and 22% stated it was "excellent." Responses regarding the relative influence of maternal or paternal family histories of breast cancer on a woman's likelihood of developing breast cancer also varied. The majority of respondents (53%) identified the

maternal family history of breast cancer as most important while only 2% identified the paternal family history as most important. Twenty-seven percent of respondents stated that maternal and paternal family histories were equally important in understanding a woman's likelihood of developing breast cancer.

Cancer Concern

Respondents' expressed concern that they would develop cancer in their lifetime also varied (see Table 1). The majority of respondents were either "very" (25%) or "somewhat" (42%) concerned while only 20% indicated that they were "not very" concerned and 12% were "not at all" concerned.

Interest in Learning of a Genetic Predisposition for Cancer

Individuals' expressed interest in being informed if they possessed a genetic predisposition for cancer was high with 87% of respondents indicating that they would like to be told if they possessed such a genetic predisposition (see Table 1). Only 10% of respondents specifically indicated that they would not be interested in knowing this information while an additional 3% of respondents either refused to answer the question or did not know what they would want under the circumstances. Among female survey respondents, interest was even higher in knowing whether they possessed a genetic predisposition that specifically increased their risk for breast cancer (see Table 1). Ninety-three percent of respondents (93%) stated that they would like to be told of a genetic predisposition for breast cancer with only 5% stating an explicit disinterest in such information. The remaining 2% of female respondents either refused to answer the question or stated they did not know what they would prefer.

Variables Associated With Interest in Genetic Cancer Predisposition

Cancer Concern and Understanding of Genetics. Relationships between interest in knowing whether one possessed a genetic predisposition for cancer in

general or breast cancer in particular (yes vs. no) and ratings of cancer concern (very, somewhat, not very, not at all) and understanding of genetics (poor, average, good, excellent) were examined using 2 X 4 chi square analyses. No significant relationships were found between self-reported understanding of genetics and either interest in knowing whether one possessed a genetic predisposition toward cancer in general ($X^2 (3) = 0.35$; n.s.) or breast cancer in particular ($X^2 (3) = 0.34$; n.s.). Similarly, no significant relationships were found between cancer concern and interest in knowing whether one possessed a genetic predisposition toward cancer in general ($X^2 (3) = 2.17$; n.s.) or breast cancer in particular ($X^2 (3) = 0.10$; n.s.).

Demographic Characteristics. Relationships between demographic variables (i.e., age, race, education, gender, and annual household income) and interest in knowing whether one possessed a genetic predisposition for cancer were examined using chi-square analyses (see Table 2). Greater education was significantly associated with a greater interest in knowing whether one either possessed a predisposition for cancer in general ($X^2 (1) = 3.81$; $p = .05$) or breast cancer specifically ($X^2 (1) = 7.59$; $p < .01$). Race was also significantly associated with interest in knowing whether one possessed a predisposition for cancer, but only for interest in knowing whether one possessed a predisposition for breast cancer in particular ($X^2 (1) = 15.41$; $p < .0001$). Non-caucasian (i.e., minority) respondents expressed greater reluctance to know if they possessed a genetic predisposition toward breast cancer than caucasian respondents (24% vs. 4%). However, interest in knowing whether one possessed a predisposition toward cancer in general was not significantly associated with gender, race, or income. Similarly, interest in knowing whether one possessed a predisposition toward breast cancer in particular was not significantly associated with income.

The relationship between age and interest in knowing whether one possessed a genetic predisposition toward cancer was examined using point-biserial correlations. No significant relationships were found between age and either interest in predisposition toward cancer in general ($r(629) = -.06$; n.s.) or breast cancer in particular ($r(344) = -.04$; n.s.).

Emotional Status. Relationships between MOS-20 Mental Health subscale scores and interest in knowing whether one possessed a predisposition toward cancer were examined using point biserial correlations. No significant relationships were found between Mental Health Subscale scores and interest in knowing whether one possessed a genetic predisposition toward cancer in general ($r(624) = .04$; n.s.) or breast cancer in particular ($r(340) = .00$; n.s.).

Health Care Access. Relationships between various indices of health care access and interest in knowing whether one possessed a predisposition to cancer in general or breast cancer in particular were examined using chi-square analyses (see Table 2). No significant relationships were obtained between interest in knowing whether one possessed a genetic predisposition to cancer in general and whether one had medical insurance coverage (private or public), having a regular doctor, or self-reported ease of access to a medical facility.

The relationship between interest in knowing of a breast cancer predisposition and possessing medical insurance, either public or private, narrowly missed the .05 level of significance ($X^2(1) = 2.94$; $p < .09$). No significant relationships were found between interest in knowing of a genetic predisposition to breast cancer and having a regular doctor or ease of access to a medical facility.

Protective Health Behaviors. Relationships between HEALTH BEHAVIOR scores and interest in genetic risk status for cancer in general and breast cancer in

particular were examined using chi-square analyses. Results indicated a significant relationship between HEALTH BEHAVIOR SCORES and interest in genetic risk status for cancer in general ($X^2(3)=12.79$; $p \leq .01$) and a marginally significant relationship for interest in genetic risk for breast cancer in particular ($X^2(3)=6.41$; $p < .10$). As shown in Table 2, engaging in fewer health protective behaviors was generally associated with less interest in genetic cancer risk status.

The relationship between interest in genetic risk status information and reports of appropriate or inappropriate mammography screening were examined for female respondents by chi-square analysis. As shown in Table 2, no significant relationships were found between mammography screening and either interest in learning of a genetic predisposition to cancer in general ($X^2(1)=0.00$; n.s.) or breast cancer in particular ($X^2(1)=0.46$; n.s.).

Multivariate Predictors of Interest in Genetic Cancer Predisposition

A logistic regression analysis was conducted to examine multivariate predictors of expressed interest in knowing whether one possessed a genetic predisposition to cancer in general. Predictor variables included age, gender, race (non-minority vs. minority), educational level ($\leq$ high school vs. $\geq$ high school degree), concern about developing cancer ("very" or "somewhat" vs. "not very" or "not at all"), Mental Health subscale score (low, moderate, or high distress based upon trichotomization of score distribution), understanding of genetics ("excellent" or "good" vs. "average" or "poor"), insurance status (no insurance vs. private or public insurance), and HEALTH BEHAVIOR scores (3 health behaviors endorsed vs 0 to 2 health behaviors endorsed). Results of this analysis is displayed in Table 3. The set of predictor variables was significantly associated with expressed interest in knowing whether one

expressed interest in knowing whether they possessed a genetic predisposition for breast cancer. This confirms previous reports documenting high levels of interest in taking a test to assess genetic risk for colon cancer among Utah residents [9] and genetic risk for breast-ovarian cancer in first degree female relatives of women with ovarian cancer [10] and breast cancer [11].

The present data also suggest that the high levels of interest in learning genetic cancer risk status evident in the somewhat unrepresentative samples employed in previous studies [9-11] may also be present in the general population. Comparison of our sample with 1990 U.S. census data [18] suggests that while our sample was more educated than the state population as a whole, our sample was very similar to the general U.S. population with regard to educational attainment. Specifically, the percentages of individuals with high school (80%) and four year college degrees (21%) in our statewide sample were virtually identical to the proportions in the general U.S. population (78% and 21%, respectively). Conversely, while minority respondents were underrepresented in our sample (7%) relative to the U.S. population (20%; [18], our sample did reflect the 8% minority population in Kentucky [18]. Since both minority status and less education were associated with less interest in genetic cancer risk information, our data may slightly overestimate interest among Kentucky residents (due to underrepresentation of lesser educated individuals) as well as the U.S. population as a whole (due to underrepresentation of minorities). Even taking this into account, however, our data still suggest that the vast majority of the general population would be interested in learning of a genetic predisposition to cancer. Even among minority respondents, for instance, 82% indicated an interest in learning of a genetic predisposition to cancer in general and 76% to breast cancer in particular.

While overall interest in learning of a genetic predisposition to cancer was very high in our sample, it was not universal. Our attempts to identify variables associated with interest in genetic cancer risk information produced mixed results. Contrary to our hypothesis, current distress and age were not linked to interest in genetic cancer risk information. Both variables were associated with interest in genetic testing for risk for breast-ovarian cancer in women with a history of ovarian cancer in a first degree relative [10]. Differences in the measure of emotional status used, the wording of the question gauging interest in genetic risk information, and the small effect sizes reported in this earlier study, may account for the failure to replicate these relationships. Additionally, we found only modest evidence to support our hypothesis that better access to health care would be associated with greater interest in genetic cancer risk status. The univariate relationships between interest in genetic cancer risk status and our health care access variables (i.e.,, having a personal physician or health insurance, difficulty in accessing a medical care facility) were all in the anticipated direction (see Table 2). However, only the relationship between lack of health insurance and less interest in learning of a genetic risk for breast cancer attained our criterion of statistical significance.

Consistent with our hypothesis, we found some evidence to suggest that engagement in a variety of health protective behaviors was associated with greater interest in learning genetic risk status for cancer in general and breast cancer in particular (see Tables 2 and 3): To the degree that more frequent engagement in a variety of health protective behaviors is indicative of a greater, generalized, interest and concern about health, our findings support the Health Belief Models's contention that individual differences in general

possessed a genetic predisposition for cancer in general (Model chi square = 20.604, 11 df; $p < .05$). While the HEALTH BEHAVIOR variable (odds ratio=1.84; $p < .05$) was the only significant predictor of interest in knowing whether one had a genetic predisposition to cancer in general, minority status (odds ratio=.51; $p=.10$) approached the .05 criterion for significance. In general, greater interest in knowing of a personal genetic predisposition to cancer was associated with non-minority status and reports of engaging in all three of the specific health behaviors assessed.

A similar logistic regression analysis was performed using interest in learning of a personal genetic predisposition to breast cancer as the dependent variable. The set of predictor variables used was the same as in the previous analysis with the exception that gender was not included because only females responded to this question. Results of this analysis are also shown in Table 3. The set of predictor variables was significantly associated with interest in knowing whether one possessed a genetic predisposition to breast cancer (model chi square = 28.427, df=10; $p<.002$). Both education (odds ratio=4.45; $p<.05$) and race (odds ratio=.13; $p<.001$) were significant predictors of interest in learning of a genetic predisposition to breast cancer. Non-minority status and possession of more than a high school education were associated with greater interest in learning of a genetic predisposition to breast cancer.

Discussion

A high level of interest in knowing whether one possessed a genetic predisposition for cancer was evident in this statewide sample. Eighty-seven percent of respondents indicated they would want to be told if they had a genetic predisposition for cancer. Ninety-three percent of female respondents

health motivation are important in understanding differences in engagement in specific health protective behaviors [13-15]. In contrast, appropriate participation in screening mammography was not associated with interest in genetic cancer risk status (Table 2). Why this was so is unclear. However, because of the small number of women in these analyses ($n=224$) and the low base rate of disinterest in genetic cancer risk information (6-11%), caution should be exercised in interpreting these results.

While we advanced no specific hypotheses regarding the relationship between race and interest in genetic cancer risk status, minority status emerged as the single best predictor of interest in learning of a personal genetic predisposition to breast cancer. This was true for both univariate and multivariate analyses. In the multivariate context, minority status was also a marginally significant predictor ($p=.10$) of interest in genetic risk status for cancer in general. The relatively small number of minority respondents included in these analyses ($n=25$ to 40) precludes drawing of firm conclusions regarding the relationship between minority status and interest in genetic cancer risk information. However, it has been suggested that minority individuals might be less interested in genetic cancer risk information due to a greater distrust of medical research [19-20].

While we documented several statistically significant predictors of interest in learning of genetic cancer risk status, the magnitude of our effects was generally small. Thus, while there clearly is a subset of the general population which does not desire information regarding personal genetic risk for cancer, accurate prediction of exactly who these individuals are is difficult. However, based on results from both this as well as preceding studies, variables which show the most promise at this time include perceptions of personal cancer

risk [9-10], education, minority status, and extent of engagement in a variety of health protective behaviors.

Two other findings also merit note. First, while self-reported understanding of genetics was not associated with interest in genetic cancer risk status, only 53% of respondents characterized their understanding of genetics as "good" or "excellent." This suggests that efforts to educate the public and the individual regarding genetic testing for cancer risk will likely need to be tailored to accommodate substantial numbers of people with a less than good understanding of genetics. Second, only a minority of our respondents (27%) indicated that both maternal and paternal family histories of breast cancer were equally important in determining the likelihood that a woman will develop breast cancer. The majority of respondents (53%) indicated that the maternal history was most significant in this regard. While it is well known that a history of breast cancer in first degree female relatives increases a woman's lifetime breast cancer risk [21-22], risk for breast cancer caused by a specific genetic mutation such as BRCA1 is associated with the history of breast cancer in both maternal and paternal lineages. Since our data suggest a predominant perception that paternal family history is less important in assessing a woman's breast cancer risk, educational efforts regarding genetic testing for the BRCA1 gene may need to specifically address this distinction between inherited and noninherited breast cancers. Failure to recognize the importance of the paternal family history in cases of inherited breast cancer could contribute to a misperception that men need not be concerned about their own BRCA1 status or that breast cancer in the paternal family does not confer any additional risk upon a daughter.

Several limitations to this study must be noted. First, while we asked

women about their interest in learning of a genetic predisposition to breast cancer specifically, all respondents were queried regarding their interest in learning of a genetic predisposition to cancer "in general." This latter question may be somewhat misleading since genes presently known to increase cancer risk tend to predispose to cancer at a specific site (e.g., colon) rather than "in general." However, some genes, such as the BRCA1 gene, can predispose to cancer at multiple sites, thus making our question regarding interest in learning of a general predisposition to cancer less misleading than it might seem. Second, while statistically significant, the magnitude of many of our obtained effects were rather small, often involving differences of only 5% or so between groups (see Table 2). The low base rate of expressed disinterest in learning of a genetic predisposition to cancer in general (10%) or breast cancer in particular (5%) makes it difficult to identify strong predictors of interest in this information. Third, while we found that several demographic, health behavior, and health care-related variables were associated with interest in learning of a genetic predisposition to cancer, there are other variables not measured that could potentially account for variance in interest in this information. For example, dispositional optimism [23] or informational preferences (blunting vs. monitoring; [24]) are likely to affect interest in cancer risk information. Additionally, existing conceptual models of health protective behavior, such as the Health Belief Model [13, 15] or the Theory of Reasoned Action [25] suggest other potentially critical variables that are likely to be associated with preferences for genetic risk information. These include perceptions of cancer susceptibility, social norms associated with testing, as well as the cost-benefit ratio associated with knowledge of genetic risk information. A fourth study limitation regards our assessment of interest

in learning of a personal genetic predisposition to cancer as opposed to, or in addition to, interest in undergoing genetic testing. Determinants of interest in learning of test results might differ from determinants of interest in undergoing genetic testing. Since the latter is a necessary precursor to the former, it is equally, if not more important to identify critical determinants of interest in submitting to genetic testing in the first place.

Finally, verbal expressions of interest in learning one's genetic risk for cancer may not predict engaging in the behaviors necessary to realize this information (e.g., blood testing). Prior studies have found a gap between interest in presymptomatic genetic testing for Huntington's Disease and the actual use of such testing [26-27]. The same gap might exist between interest and action with regard to genetic testing for cancer. Admittedly, Huntington's disease might be a poor analogy because knowledge of one's genetic risk status confers little or no health benefit: disease onset cannot be prevented and the disease is incurable [28]. However, while the potential benefits of genetic cancer risk information might include reductions in cancer-related worry in non-carriers of the gene or increased participation in cancer detection or prevention programs [1-2], no research, as yet, has documented these benefits. As suggested by the Health Belief Model, participation in presymptomatic testing for genetic cancer risk may be dramatically affected by the perception of the relative costs and benefits of testing. Future research should assess these perceptions as well as intentions to actually engage in the behaviors necessary to obtain this knowledge (e.g., blood testing).

In conclusion, our data indicate that interest in testing for genetic cancer susceptibility is likely to be high. However, it is also likely that many of those individuals requesting testing will poorly understand the

implications of test results. As a result, effective genetics counseling, both prior to and following testing, will be necessary [3, 19]. Furthermore, our findings, as well as that of others [9-10], suggest that those individuals least likely to participate in genetic testing for cancer risk might be those who are unlikely to engage in other health protective behaviors, those most likely to be sociodemographically dissimilar to health professionals (i.e., minorities and lesser educated), those relatively disconnected from the health care system (i.e., without health insurance), and those who perceive little personal cancer risk. Many of these factors are associated with less than optimal utilization of other cancer control activities such as routine screening for cervical and breast cancers [29-32]. As a result, when genetic mutation testing for cancer susceptibility becomes widely available to the general public, promotion of effective utilization of this technology may confront challenges similar to those encountered in promoting other cancer control activities such as screening for cervical or breast cancer [29-32].

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Table 1

Responses to Survey Questions Regarding Understanding of Genetics, Cancer Concern, and Interest in Genetic Testing.

QUESTION/RESPONSE	% OF SAMPLE
UNDERSTANDING OF GENETICS?^a	
Poor	9%
Average	34%
Good	31%
Excellent	22%
Don't know	5%
CONCERN OVER HAVING CANCER DURING LIFETIME?^a	
Very	25%
Somewhat	42%
Not Very	20%
Not at all	12%
Don't know	1%
WANT TO BE TOLD OF PERSONAL GENETIC CANCER PREDISPOSITION?^a	
Yes	87%
No	10%
Don't know/Refuse	3%
WANT TO BE TOLD OF PERSONAL GENETIC BREAST CANCER PREDISPOSITION?^b	
Yes	93%
No	5%
Don't know/Refuse	2%

^a Total respondents ($n = 649$); ^b Female respondents only ($n = 355$)

Table 2

Relationship Between Interest in Knowing of a Personal Predisposition to Cancer and Demographic, Health Care Access, and Protective Health Behavior Variables.

VARIABLE	<u>CANCER IN GENERAL</u>		<u>BREAST CANCER</u>	
	% NOT INTERESTED	<u>n</u>	% NOT INTERESTED	<u>n</u>
DEMOGRAPHIC				
Race				
Caucasian	10	(58/587)	4	(12/321) **
Non-caucasian	18	(7/40)	24	(6/25)
Education				
≤ High School Degree	13	(44/345) **	9	(16/189) **
> High School Degree	8	(22/287)	1	(2/157)
Gender				
Male	12	(33/288)	--	--
Female	10	(33/345)	--	--
Household Income				
< \$15K	12	(17/138)	7	(7/100)
\$15K - \$30K	10	(16/174)	3	(3/87)
\$30K - \$50K	7	(10/141)	1	(1/69)
> \$50K	15	(18/121)	7	(3/43)
HEALTH CARE ACCESS				
Have Regular Doctor				
Yes	10	(53/536)	5	(14/296)
No	13	(13/97)	8	(4/51)

Table 2 (cont.)

Private Insurance

Yes	10	(49/489)	4	(9/247) **
No	12	(17/144)	9	(9/100)

Ease of Access to Medical Facility

Very Easy	9	(31/388)	4	(8/187)
Somewhat Easy	11	(21/191)	7	(6/93)
Somewhat Difficult	12	(9/73)	4	(2/49)
Very Difficult	13	(3/23)	13	(2/15)

PROTECTIVE HEALTH BEHAVIORS

HEALTH BEHAVIOR Scores

0	18	(7/39)***	9	(2/22)*
1	20	(26/131)	10	(7/68)
2	12	(27/221)	10	(12/123)
3	8	(20/256)	3	(4/141)

Recent Mammography History^a

Appropriate	11	(16/148)	6	(9/139)
Inappropriate	11	(9/85)	9	(8/85)

^a Only female respondents $\geq$ 40 years of age; classified by ACS guidelines

*** $p < .01$ (chi-square test)

** $p < .05$ (chi-square test)

* $p < .10$ (chi-square test)

Table 3

Logistic Regression Analysis of Interest in Being Informed of Personal Genetic Cancer Predisposition.

VARIABLE	TYPE OF GENETIC CANCER PREDISPOSTION?			
	CANCER IN GENERAL?		BREAST CANCER?	
	OR	95% CL	OR	95% CL
Race ^a	0.51*	.23 - 1.14	0.12***	0.04 - 0.43
Education ^b	1.51	.87 - 2.66	4.45**	1.16 - 16.99
Age				
40-59 yrs vs. $\leq$ 39 yrs.	1.34	.75 - 2.40	1.20	0.35 - 4.06
$\geq$ 60 yrs vs. $\leq$ 39 yrs.	1.24	.63 - 2.42	0.52	0.15 - 1.76
Gender ^c	1.23	.74 - 2.05	--	-- --
Cancer Concern ^d	1.50	.87 - 2.57	2.24	0.77 - 6.54
Understanding of Genetics ^e	1.10	.66 - 1.83	0.76	0.28 - 2.01
Medical Insurance ^f	1.32	.69 - 2.57	1.67	0.52 - 5.40
Current Distress				
Moderate vs. Low	0.85	.45 - 1.64	1.18	0.28 - 5.02
High vs. Low	0.73	.40 - 1.35	0.60	0.18 - 2.00
HEALTH BEHAVIOR ^g	1.84**	1.01 - 3.36	2.05	0.52 - 8.07
MODEL CHI-SQUARE		20.60**		28.43***

* $p < .10$; ** $p < .05$; *** $p < .01$

Note: OR = odds ratio; 95% CL = 95% confidence limit.

^a minority vs. caucasian; ^b high school degree or more vs. some high school or less; ^c female vs. male; ^d very or somewhat concerned vs. a little or not at all concerned; ^e excellent or good vs. average or poor; ^f health insurance vs no health insurance; ^g 0-2 health behaviors vs. 3 health behaviors reported