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This report summarizes activities during the third year of a four year predoctoral research training program in biopsychosocial aspects of breast cancer. Three research trainees were supported during the third year of the training program. One of these trainees was supported during the second year of the training program while the remaining two were new appointees. Research training was provided by a multi-disciplinary 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 third year of the training program centered around the UK Multidisciplinary Breast Care Center. Research activities supported during the first three years of the training program have resulted in a total of 9 manuscripts published or in press with an additional 11 manuscripts currently in various stages of the peer review process.

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Melissa Aubry-Lewis 9-5-97

PI - Signature Date

TABLE OF CONTENTS

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 third year of a four year predoctoral research training program in biopsychosocial aspects of breast cancer. Dates of the training program are August 15, 1994 to August 14, 1998, inclusive. 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). Funding is provided for support of three predoctoral trainees each year. This support includes a monthly stipend and full payment of all graduate school tuition and fees.

6. BODY

TRAINEES DURING PROJECT YEAR THREE:

The third year of the research training program began on August 15, 1996. Three predoctoral trainees were appointed and began one year terms as of that date. One of the three trainees, Lauren Cunningham, a doctoral student in Psychology, was a reappointee from the second year of the training program. The two new trainees appointed for the third year of the training program both possessed Masters degrees in their respective fields and were pursuing doctoral studies in Psychology at the University of Kentucky. One of the two new appointees, Jamie Studts, had completed a Master's degree in Counseling Psychology, and already possessed some prior research experience in an oncology setting. The other new appointee, Matt Cordova, possessed a Masters degree in Clinical Psychology, and also possessed some prior research experience in an oncology setting.

The three trainees appointed for the 1996-1997 project year were chosen following a campus-wide recruitment process conducted during the spring of 1996. The availability of one-year predoctoral research trainee positions focusing upon breast cancer was advertised throughout both the medical center and main campuses at the University of Kentucky. A total of 9 completed applications were received. These 8 applications spanned a variety of disciplines including Nursing, Communications, and various subdisciplines of Psychology including counseling, clinical, and social psychology. Following review of the entire pool of applicants the three individuals indicated above were offered training positions for the third year of the training program. While it was deemed less than desireable that all three trainees be doctoral candidates in Psychology, the three individuals that were selected clearly represented the "cream of the crop" with respect to past research accomplishments, current research skills, and future research potential.

RECENT STATUS OF TRAINEES FROM PROJECT YEARS ONE AND TWO:

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 two manuscripts for publication based upon her dissertation research. Upon completion of her clinical internship in September of 1997 Dr. Curran assumed a position as director of the orofacial pain clinic at the University of Minnesota College of Dentistry.

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 accepted a position as an NIMH postdoctoral research trainee at the University of Kentucky, beginning in June of 1996. She continues in this position at the present time. This postdoctoral position is allowing her to receive additional research training in behavioral oncology under the direction of Michael Andrykowski, Ph.D. Three manuscripts based upon her dissertation are either published or in press. In addition, several additional manuscripts based upon her postdoctoral research with breast cancer patients have been submitted for publication in various peer-reviewed journals. Dr. Carpenter recently was named the 1997-1998 recipient of a prestigious research grant award from the Oncology Nursing Research Foundation. This one year award will provide funding for her research entitled "Circadian Rhythmicity of Hot Flashes Following Treatment For Breast Cancer."

TRAINING PROGRAM ACTIVITIES DURING PROJECT YEAR THREE:

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) formal, graduate level coursework. Each of these components was effectively implemented during the third year of the training program.

As part of the training program, all trainees must complete two specific semester-long graduate level courses at the University of Kentucky. One course is entitled "Psychosocial Oncology" and is an upper level survey course examining the content, theory, and methods involved in the study of the behavioral, social, and psychological aspects of cancer. All three of the trainees during project year three had previously completed this course during the Fall semester, 1995. The second required course is entitled "Integrated Research Methods in Medical Behavioral Science." This course is an upper level course emphasizing content and application of research methods drawn from a variety of behavioral and social science disciplines (e.g., anthropology, sociology, psychology, epidemiology) to the study of medical and health-related research questions. Two of the trainees completed this course during the spring semester of 1996 while the remaining trainee (Studts) had completed the course during the spring semester of 1995.

Thus all three trainees supported during 1996-1997 have completed the formal required coursework associated with the research training program.

A monthly meeting of the training program faculty and predoctoral trainees continued to be held during the third year of the training program. Other faculty, graduate students, and postdoctoral fellows interested in biopsychosocial breast cancer research were also invited to attended 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 third year of the training program, all three predoctoral research trainees were actively involved in one or more specific research projects under the supervision of training program faculty. These research projects included: (a) an investigation of the incidence, severity, and predictors of post-mastectomy pain syndrome following breast cancer treatment; (b) an investigation of symptoms of post-traumatic stress disorder (PTSD) in women previously treated for early-stage breast cancer; (c) an investigation of the incidence, severity, and predictors of menopausal symptoms following treatment for breast cancer; (d) a longitudinal investigation of the psychological and behavioral impact of undergoing a benign breast biopsy or fine needle aspiration for diagnostic purposes, (e) a laboratory study of emotional expression in women with breast cancer compared to healthy women without a history of breast cancer, and (f) a population survey of Kentucky residents regarding knowledge of hereditary risk for breast and ovarian cancer and interest in clinical testing for that risk. 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, each of the trainees is responsible for the development and implementation of their own individual research project. Generally, this individual research project serves to satisfy the research requirement for the Master's or Doctoral degree. In each instance, the individual trainee assumes full responsibility for the conduct of all phases of the research. All individual research projects are conducted under the supervision of training program faculty with one or more members of the training program faculty serving as members of the student's thesis or dissertation committee. During project year three, Lauren Cunningham completed a manuscript based upon her Master's thesis research investigating breast cancer risk perceptions, screening behavior, and psychological adjustment of women with benign breast problems. This manuscript was accepted for publication by Health Psychology. During project year three, Jamie Studts completed data collection for his project investigating the short and long-term impact of participating in an educational seminar focusing upon hereditary breast and ovarian cancer. Finally, during project year three, Matt Cordova began development of his dissertation research which will focus upon cognitive processing of the trauma associated with breast cancer and its impact upon subsequent psychological adjustment.

Each of the communal research projects "a" through "e" listed above utilized women treated for breast cancer or undergoing breast diagnostic procedures 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, typically 4-5 hours per week, in the Breast Care Center. This allows them to become very familiar with the milieau and culture in which breast cancer treatment is embedded.

A large number of manuscripts have stemmed directly from research activities supported by the training program. A total of 9 manuscripts are currently published or in press. These are listed below and copies of published manuscripts are provided in the Appendix. Seven more manuscripts have been submitted for publication and are presently under peer review. These are listed at the end of this section. Four additional manuscripts are presently undergoing revision prior to resubmision to a peer-reviewed journal. These are also listed at the end of this section.

During the third year of the training program, each of the three trainees attended the annual meeting of the Society of Behavioral Medicine, held in San Francisco in April of 1997. Partial support for travel expenses to attend this conference was furnished by the training grant. Each of the trainees presented a poster based upon research work supported by the training grant. The titles of these research poster presentations are listed at the end of this section.

Finally, recruitment of predoctoral research trainees for the fourth and final year of the training project occurred in the spring of 1997. As usual, the availability of one-year predoctoral research trainee positions focusing upon breast cancer was advertised throughout both the medical center and main campuses at the University of Kentucky. A total of 7 completed applications were received (including applications from each of the trainees supported during 1996-1997.) These 7 applications again spanned a variety of disciplines including Sociology, Communications, and various subdisciplines of Psychology including counseling, clinical, and social psychology. Following review of the entire pool of applicants it was decided to reappoint each of the three current trainees to an additional year of training support. Based upon the pool of applicants, these three individuals clearly were the best training candidates, both in terms of past accomplishments as well as future research potential. Additionally, a great deal of value was placed upon the opportunity to provide more advanced training for these three individuals. Both Lauren Cunningham and Matt Cordova were in the process of planning dissertation research projects expanding upon their prior research in breast cancer. Additionally, Jamie Studts was involved in the analysis and write-up of his breast cancer-related Master's thesis.

MANUSCRIPTS PUBLISHED OR IN PRESS

Carpenter, J.S. (in press). Informing participants about the benefits of descriptive research. Nursing Research

Cunningham, L.C., Andrykowski, M.A., Wilson, J.F., McGrath, P.C., Sloan, D.A., & Kenady, D.E. (in press). Physical symptoms, distress, and breast cancer risk perceptions in women with benign breast problems. Health Psychology.

Andrykowski, M.A., & Cordova, M.J. (in press). Factors associated with reports of PTSD symptoms following breast cancer treatment: Test of the Andersen model. Journal of Traumatic Stress.

Carpenter, J.S. (in press). Self-esteem and well-being among women with breast cancer and age-matched comparison women. Journal of Psychosocial Oncology.

Andrykowski, M.A., Lightner, R., Studts, J.L., & Munn, R.K. (1997). Hereditary risk notification and testing: How interested is the general population. Journal of Clinical Oncology, 15, 2139-2148.

Carpenter, J.S. (1996). Applying the Cantril methodology to study self-esteem: Psychometrics of the self-anchoring self-esteem scale. Journal of Nursing Measurement, 4, 171-189.

Andrykowski, M.A., Curran, S.L., Studts, J.L., Cunningham, L., Carpenter, J.S., McGrath, P.C., Sloan, D.A., & Kenady, D.E. (1996). Psychological adjustment and quality of life in women with breast cancer and benign breast problems: A controlled comparison. Journal of Clinical Epidemiology, 49, 827-834.

Andrykowski, M.A., Munn, R.K., & Studts, J.L. (1996). Interest in learning of a personal genetic predisposition for cancer: Results of a general population survey. Preventive Medicine, 25, 527-536.

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

Carpenter, J.S., Andrykowski, M.A., Cordova, M., Cunningham, L., Studts, J., McGrath, P., Kenady, D., Sloan, D., & Munn, R. (1997). Hot flashes in postmenopausal women treated for breast cancer: Prevalence, severity, correlates, management, and relation to quality of life. (submitted to Cancer)

Carpenter, J.S., Andrykowski, M.A., Sloan, P. Cunningham, L.L.C., Cordova, M., Studts, J., McGrath, P., Sloan, D., & Kenady, D. (1997). Post-mastectomy pain: Prevalence, characteristics, correlates, and relation to quality of life. (submitted to Journal of Clinical Epidemiology)

Cordova, M.J., Andrykowski, M.A., Hann, D.M., & Jacobsen, P.B. (1997). Symptom structure of PTSD following breast cancer. (submitted to Journal of Abnormal Psychology)

Andrykowski, M.A., Curran, S.L., & Lightner, R. (1997). Fatigue following treatment for breast cancer: A controlled comparison. (submitted to Journal of Behavioral Medicine)

Andrykowski, M.A., Cordova, M.J., Studts, J.L., & Miller, T.W. (1997). Diagnosis of posttraumatic stress disorder following treatment for breast cancer. (submitted to Journal of Consulting and Clinical Psychology)

Cordova, M.J., & Andrykowski, M.A. (1997). Psychosocial sequelae of cancer: Toward a transition paradigm. (submitted to American Psychologist)

Carpenter, J.S., Andrykowski, M.A., Cordova, M.J., Cunningham, L.L.C., & Studts, J.L. (1997). Do participants' reports of symptom prevalence or severity vary by interviewer gender? (submitted to Nursing Research)

MANUSCRIPTS UNDERGOING REVISION PRIOR TO RESUBMISSION FOR PEER REVIEW

Curran, S.L., & Andrykowski, M.A. (1997). Diurnal patterns of fatigue, mood, and pain, following breast cancer treatment. (previously submitted to Health Psychology)

Curran, S.L., Andrykowski, M.A., Studts, J.L., Cunningham, L., Carpenter, J.S., McGrath, P.C., Sloan, D.A., & Kenady, D.E. (1997). Rheumatologic symptoms following breast cancer treatment: A controlled comparison. (previously submitted to Journal of Pain and Symptom Management)

Valentino, J., Andrykowski, M.A., Lightner, R., & Wood, T. (1997). Population attitudes toward oncology clinical trials. (previously submitted to Journal of Clinical Oncology)

Andrykowski, M.A., Cordova, M.J., McGrath, P.C., Sloan, D.A., & Kenady, D.E. (1997). Stability and change in PTSD-like symptoms following breast cancer treatment: A one year follow-up. (previously submitted to Journal of Consulting and Clinical Psychology)

TRAINEE POSTER PRESENTATIONS AT PROFESSIONAL CONFERENCES

Studts, J.L., Munn, R.K., Gallion, H.H., & Andrykowski, M.A. (April, 1997). A psychoeducational group intervention for persons interested in BRCA1 testing: Preliminary results. Poster presented at the Annual Meeting of the Society of Behavioral Medicine, San Francisco, CA.

Cunningham, L.C., & Andrykowski, M.A. (April, 1997). Symptom reporting and psychological correlates in women with fibrosystic breast disease. Poster presented at the Annual Meeting of the Society of Behavioral Medicine, San Francisco, CA.

Cordova, M.J., Andrykowski, M.A., & Jacobsen, P.B. (April, 1997). Symptom structure of PTSD following breast cancer. Poster presented at the Annual Meeting of the Society of Behavioral Medicine, San Francisco, CA.

7. CONCLUSIONS

Each of the six components of the research training program were effectively implemented during the third 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.

The fourth year of the project will be devoted to completion of the numerous existing communal research projects (see above), as well as implementation of one or two additional communal projects. For example, a laboratory based project to compare the behavioral and endocrine responses of women with and without breast cancer to a standard laboratory stress paradigm has recently received approval by the local institutional review board. Additionally, as indicated earlier, two of the trainees will be developing and implementing dissertation research projects related to breast cancer whil the third trainee will be completing a breast cancer-related master's thesis.

8. REFERENCES

None.

9. APPENDIX

Nine publications have resulted directly from training program research activities at the time of this writing. Five of these have been published while four are still in press. Copies of the five published manuscripts are included in the appendix.

APPENDIX

Journal of Consulting and Clinical Psychology
1995, Vol. 63, No. 6, 981-986

0022-006X/95/$3.00

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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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, Threatt, 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 postcompletion of all primary breast cancer therapy (i.e., surgery, chemotherapy, radiotherapy); and (d) participants in a previous study of posttreatment 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 >80,000.

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-Fluourouracil (5-FU; n = 9), cyclophosphamide and doxirubicin (n = 9); 5-FU, cyclophosphamide, and doxirubicin (n = 4); and 5-FU, cyclophosphamide, doxirubicin, 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 1
Descriptive Statistics and Internal Consistencies for IES and PCL–C Scale and Subscales

Measure	*M*	*SD*	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 $ps < .01$.

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

	Dependent variable	
Predictor 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 Rs for IES and PCL–C were .500 and .562, respectively; percentages of variances accounted for were 25.0 and 31.6, respectively; and Fs(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 women 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 questionnaires 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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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) has 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). Breast cancer 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 that the BC group reported (1) poorer physical health and functioning, (2) no differences in psychological distress, and (3) 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. J CLIN EPIDEMIOL 49;8:827–834, 1996.

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 on psychological distress and QOL: cross-sectional research designs with the inclusion of comparison groups of individuals without malignancy (e.g., see Refs. 3–5) and prospective, longitudinal research designs with or without the inclusion of nonmalignant comparison groups (e.g., see Refs. 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 on 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 postdiagnosis) 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 on 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 nonmalignant breast problems (cf. Refs. 14 and 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 2 years postmastectomy 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 1 year postmastectomy 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 following breast surgery reported greater psychological distress then women with benign breast disease [11]. In summary, results consistently suggest greater distress in women with breast cancer 1 to 2 years following breast surgery relative to women with benign breast disease.

The conclusions that can be drawn from research comparing psy-

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chological 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 nonoverlapping to a degree in the general population. Because 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 (1) involve major life changes, (2) are lasting in their effects, and (3) 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 benign breast problem (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 postcompletion 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 (Lexington, KY). 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 functioning, 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 effect. 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 seven-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 postdiagnosis 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. On the basis of 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 0.05 was used as the criterion for statistical significance. No correction for multiple statistical analyses was employed for two reasons: (1) only a relatively small number of between-group (17) and within-group (8) analyses of QOL differences for the BC and BBP groups were conducted; and (2) between-group analyses were based on 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 postdiagnosis 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). Pathological 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 of 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 only a marginally significant difference between these groups for marital status [χ^2 (1) = 2.69; $p \leq 0.10$]. Marital status (unmarried vs. married) was therefore used as a covariate in all analyses of covariance (ANCOVA).

Quality of Life: Differences Between Breast Cancer and Benign Breast Problem Groups

QUALITY OF LIFE: 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 [$F(1, 157) = 5.42$; $p < 0.05$] and MOS-Physical [$F(1, 157) = 7.38$; $p < 0.01$] scores.

Two additional "between-group" 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 [$F(1, 157) = 3.02$; not significant (NS)] or

TABLE 1. Demographic characteristics for breast cancer and benign breast problem groups

Variable	Percentage of breast cancer patients (n = 80)	Percentage of benign breast problem patients (n = 80)	χ^{2a}	p^b
Married	56	70	2.69	0.10
Income			6.48	0.17
<$15K	33	17		
$15K–$30K	19	22		
$30K–$50K	14	14		
$50K–$80K	17	27		
>$80K	17	20		
Education			4.84	0.18
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	0.35
Caucasian	91	95	0.39	0.53

[a]Chi-square test of difference between breast cancer and benign breast problem groups. Yates correction used for 2 × 2 analyses.
[b]p value associated with chi-square test.
[c]At least one post baccalaureate course or a postbaccalaureate degree.

their own previous physical health [$F(1, 157) = 1.35$; NS] (see Table 3). However, "within-group" analyses using paired t tests indicated that the BC group rated their current physical health as poorer than both the health of a typical person their age [$t(79) = 2.10$; $p < 0.05$] and poorer than their own previous health [$t(79) = 4.28$; $p < 0.001$]. In contrast, the BBP group rated their current physical health significantly better than the health of a typical person their age [$t(79) = 2.45$; $p < 0.05$] but not different from their previous health [$t(79) = 0.30$; NS].

QUALITY OF LIFE: PSYCHOLOGICAL DIMENSION. Differences between the BC and BBP groups with regard to psychological distress and adaptation were examined using separate ANCOVAs for each of five QOL indices: CPBS-Life Outlook, CPBS-Self-Respect, CES-

TABLE 2. Means and standard deviations for quality of life indices for breast cancer and benign breast problem groups

QOL dimension/variable	Mean[a] Breast cancer (n = 80)	Mean[a] Benign breast problems (n = 80)	SD[a]	F^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	0.45
PANAS-Positive Affect	33.6	34.4	8.5	0.39
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	0.86
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 (n = 160).
[b]F value for test of difference between BC and BBP groups.
*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

TABLE 3. Means and standard deviations for Perceived Health Questionnaire ratings of health and quality of life for women with breast cancer and benign breast problems

Variable	Breast cancer (n = 80) Mean	SD	Benign breast problems (n = 80) Mean	SD	F^a
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.

*$p < 0.05$; **$p < 0.01$.

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 [$F(1, 157) = 11.82$; $p \leq 0.001$]. Women in the BC group reported greater recent improvement in their "outlook on life" relative to the BBP group.

QUALITY OF LIFE: SOCIAL DIMENSION. Differences between the BC and BBP groups with regard to social and interpersonal functioning were examined using separate analyses for each of three indices: MOS-Social, CPBS-Spouse Love, and CPBS-Spouse Relation. Results are shown in Table 2. Analysis of covariance 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 [$F(1, 128) = 14.29$; $p < 0.001$]. Similarly, women in the BC group also reported greater improvement in their relationship with their spouse/partner but these results narrowly missed meeting our 0.05 criterion for statistical significance [$F(1, 128) = 3.31$; $p = 0.07$].

QUALITY OF LIFE: SPIRITUAL DIMENSION. Differences between the BC and BBP groups with regard to the Spiritual dimension of QOL were examined using separate ANCOVAs for each of two 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 [$F(1, 157) = 8.99$; $p < 0.01$] and ascribed significantly more importance to spiritual concerns [$F(1, 157) = 4.15$; $p < 0.05$].

QUALITY OF LIFE: 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 [$F(1, 157) = 1.40$; NS] 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-group 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 [$F(1, 157) = 9.71$; $p < 0.01$]. 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 [$F(1, 157) = 1.38$; NS]. Furthermore, within-group analyses using paired t tests revealed no differences between ratings of current QOL and either QOL of a typical person their age [$t(79) = 0.21$; NS] or previous QOL [$t(79) = 1.44$; NS] 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 $t(79) = 4.97$; $p < 0.001$] and higher than their own previous QOL [paired $t(79) = 2.94$; $p < 0.01$].

Quality of Life: 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. Quality of life was largely unrelated to the disease and treatment variables examined. Only 5 of the 78 correlations (6%) computed met the 0.05 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-group analyses indicated that the BC group reported poorer physical health and functioning than the BBP group (Table 2). Second, within-group 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 differ significantly 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 psychologi-

TABLE 4. Correlations between quality of life indices and disease/treatment variables for breast cancer 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	0.07	0.04	0.40**	−0.02	−0.04	−0.13
PHQ-Current Health	0.18	0.12	0.07	0.09	−0.10	−0.10
Psychological dimension						
CPBS-Life Outlook	0.04	−0.02	0.09	0.14	−0.15	−0.06
CPBS-Self-Respect	−0.02	−0.14	0.11	0.05	−0.04	0.03
CES-Depression	−0.02	0.02	−0.16	−0.06	0.01	0.22*
POMS-Mood Disturbance	−0.07	−0.08	−0.08	−0.06	0.03	0.13
PANAS-Positive Affect	0.10	0.03	0.05	0.21	−0.17	−0.06
Social dimension						
CPBS-Spouse Love	0.13	−0.14	−0.11	0.05	−0.14	0.36**
CPBS-Spouse Relation	0.02	−0.15	0.05	−0.06	−0.21	0.22
MOS-Social	0.05	0.04	0.21	0.01	−0.06	−0.13
Spiritual dimension						
CPBS-Rel. Satisfaction	0.01	−0.12	−0.25*	0.04	−0.05	0.21
SPIRITUAL-Importance	−0.17	−0.03	−0.23*	0.02	0.02	0.14
Global QOL rating						
PHQ-Current QOL	0.06	0.14	0.08	0.09	−0.02	−0.03

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.

[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).

*$p < 0.05$; **$p < 0.01$.

cal 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 2 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 on 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. Advances in treatment and supportive care, along with increasing public awareness of breast cancer, may have created a current climate that 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 that mediate perceptions of current physical and psychosocial status [39] and that 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 on 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 one-quarter to one-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 postdiagnosis 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 on 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 on 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 the 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 positive psychosocial adaptation 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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Interest in Learning of Personal Genetic Risk for Cancer: A General Population Survey

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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 among 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.**

Key Words: **genetics; risk notification; cancer; survey.**

INTRODUCTION

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, which 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 an approximately 85% risk of developing breast cancer during their lifetime.[7] This risk exceeds the 12–13% lifetime risk of developing breast cancer among 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, edu-

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cation, 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 U.S. population. Secondarily, 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 statewide, 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, postinterview 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 1,326 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). A total of 649 calls resulted in complete telephone interviews. This constituted 55% of telephone calls to eligible households (649 of 1,183).

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 4-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 4-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 families equally?

Protective health behaviors. Four questions assessed respondent's performance of protective health behaviors. Questions asked of all respondents included: (a) How often do you go to the dentist? (response alternatives included more frequently than every 6 months, every 6 months, every 12 months, every 2–3 years, as need arises, not at all); (b) 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 (c) 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 5 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: (a) Do you have a doctor whom you can consult whenever you have medical problems or questions? (b) Are you presently covered by private medical insurance? and (c) 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 4-point Likert scale with response alternatives ranging from "very easy" to "very difficult."

Affective status. Current affective status was assessed using the 5-item Mental Health subscale from the 20-item Medical Outcome Study Short-Form Health Survey (MOS-20[17]). All five questions were 6-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 α, was 0.87 for the Mental Health subscale.

Data Analysis

Data were analyzed using the Statistical Program for the Social Sciences–X. All 2×2 χ^2 analyses employed Yates correction. An α level of 0.05 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–

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 ($n = 355$).

88). The sample was primarily Caucasian (93%), with African-American respondents constituting 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%), postbaccalaureate 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 comprised 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 4-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 2×4 χ^2 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 [$\chi^2(3) = 0.35$; NS] or breast cancer in particular [$\chi^2(3) = 0.34$; NS]. Similarly, no significant relationships were found between cancer concern and interest in knowing whether one possessed a genetic predisposition toward cancer in general [$\chi^2(3) = 2.17$; NS] or breast cancer in particular [$\chi^2(3) = 0.10$; NS].

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 χ^2 analyses (see Table 2). Greater education was significantly associated with a greater interest in knowing whether one possessed a predisposition either for cancer in general [$\chi^2(1) = 3.81$; $P = 0.05$] or for breast cancer specifically [$\chi^2(1) = 7.59$; $P < 0.01$]. 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 [$\chi^2(1) = 15.41$; $P < 0.0001$]. 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 interest in predisposition either toward cancer in general [$r\,(629) = -0.06$; NS] or toward breast cancer in particular [$r\,(344) = 0.04$; NS].

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 [$r\,(624) = 0.04$; NS] or breast cancer in particular [$r\,(340) = 0.00$; NS].

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 χ^2 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), had a regular doctor, or had 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 0.05 level of significance [$\chi^2(1) = 2.94$; $P < 0.09$]. 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 χ^2 analyses. Results indicated a significant relationship between Health Behavior scores and interest in genetic risk status for cancer in general [$\chi^2(3) = 12.79$; $P < 0.01$] and a marginally significant relationship for interest in genetic risk for breast cancer in particular [$\chi^2(3) = 6.41$; $P < 0.10$]. 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 χ^2 analysis. As shown in Table 2, no significant relationships were found between mammography screening and interest in learning of a genetic predisposition either to cancer in general [$\chi^2(1) = 0.00$; NS] or to breast cancer in particular [$\chi^2(1) = 0.46$; NS].

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 (nonminority vs minority), educational level (<high school vs ≥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 are displayed in Table 3. The set of predictor variables was significantly associated with ex-

TABLE 2

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

Variable	Cancer in general		Breast cancer	
	% not interested	*n*	% not interested	*n*
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)
$15–30K	10	(16/174)	3	(3/87)
$30–50K	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)
Medical 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 ≥40 years of age; classified by ACS guidelines.
* $P < 0.10$ (χ^2 test).
** $P < 0.05$ (χ^2 test).
*** $P < 0.01$ (χ^2 test).

pressed interest in knowing whether one possessed a genetic predisposition for cancer in general (model $\chi^2 = 20.604$, 11 *df*; $P < 0.05$). While the Health Behavior variable (odds ratio = 1.84; $P < 0.05$) was the only significant predictor of interest in knowing whether one had a genetic predisposition to cancer in general, minority status (odds ratio = 0.51; $P = 0.10$) approached the 0.05 criterion for significance. In general, *greater* interest in knowing of a personal genetic predisposition to cancer was associated with nonminority 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 $\chi^2 = 28.427$, $df = 10$; $P < 0.002$). Both education (odds ratio = 4.45; $P < 0.05$) and race (odds ratio = 0.13;

TABLE 3

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

Variable	Type of genetic cancer predisposition?			
	Cancer in General?		Breast cancer?	
	OR	95% CL	OR	95% CL
Race[a]	0.51*	0.23–1.14	0.12***	0.04–0.43
Education[b]	1.51	0.87–2.66	4.45**	1.16–16.99
Age				
40–59 years vs ≤39 years	1.34	0.75–2.40	1.20	0.35–4.06
≥60 years vs ≤39 years	1.24	0.63–2.42	0.52	0.15–1.76
Gender[c]	1.23	0.74–2.05	—	— —
Cancer concern[d]	1.50	0.87–2.57	2.24	0.77–6.54
Understanding of genetics[e]	1.10	0.66–1.83	0.76	0.28–2.01
Medical insurance[f]	1.32	0.69–2.57	1.67	0.52–5.40
Current distress				
Moderate vs low	0.85	0.45–1.64	1.18	0.28–5.02
High vs low	0.73	0.40–1.35	0.60	0.18–2.00
Health behavior[g]	1.84**	1.01–3.36	2.05	0.52–8.07
Model χ^2		20.60**		28.43***

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.
* $P < 0.10$.
** $P < 0.05$.
*** $P < 0.01$.

$P < 0.001$) were significant predictors of interest in learning of a genetic predisposition to breast cancer. Nonminority 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 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 4-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 Model's contention that individual differences in general 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 ($P = 0.10$) 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 noncarriers 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 those 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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171-189

Applying the Cantril Methodology to Study Self-Esteem: Psychometrics of the Self-Anchoring Self-Esteem Scale

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The importance of the construct of self-esteem is evidenced by its extensive inclusion in prior research as a measure of well-being or adaptation to illness. Despite the construct's importance, current measures of self-esteem are inadequate when used among populations experiencing illnesses, such as cancer. Use of an alternative measure of self-esteem is proposed which addresses limitations of existing measures. The Self-Anchoring Self-Esteem Scale (SASES) is an adaptation of Cantril's methodology used to study quality of life, which requires individuals to subjectively define high and low endpoints of a 10-point ladder prior to providing numerical ratings. Data collected from three cross-sectional studies involving four samples of healthy individuals and women with cancer supported psychometric properties of the scale.

Self-esteem is an overall, affective evaluation of the self composed of positive and negative thoughts and feelings regarding physical, social, psychological and/or spiritual characteristics (Carpenter, 1996; Curbow, Somerfield, Legro, & Sonnega, 1990; Rosenberg, 1965). Self-esteem is considered a subjective and multidimensional construct (Carpenter & Brockopp, 1994; Mohide, Archibald, Tew, Young, Haines, 1992; Pelham & Swann, 1989; Rosenberg, 1965), and has a slightly different meaning for each person because it is an evaluation of a variety of characteristics important to each individual (Curbow et al., 1990; Morris, 1985; Rosenberg, 1979, 1981). This construct has been described as the most important aspect of the individual to study due to its positive associations with mental health and well-being (Rosenberg, 1965; Wylie, 1989).

Accurate assessment of self-esteem is crucial to understanding the impact of acute and chronic illness. Because self-esteem represents an individual's feelings about all aspects of the self, it can be used as a barometer for determining how an

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individual is responding to illness. In research assessing the impact of cancer on individuals, self-esteem has been used as an indicator of well-being (Dirksen, 1989; Felton, Revenson, & Hinrichsen, 1984; Neuling & Winefield, 1988), mental health (Dougherty, Templer, & Brown, 1986; Hobfoll & Walfisch, 1984; Spiegel, Bloom, & Yalom, 1981), quality of life (Greer & Burgess, 1987; Mohide, Archibald, Tew, Young, & Haines, 1992; Nelson, 1991; Payne, 1992; Waltz, 1986), psychosocial adjustment (Cella & Tross, 1986; Gamba et al., 1992; Jenkins & Pargamenti, 1988; Lewis, 1982, 1989; Lewis, Gottesman, & Gutstein, 1979; Penman et al., 1987; Revenson, Wollman, & Felton, 1983; Taylor, Lichtman, & Wood, 1984; Worden & Weisman, 1977; Zemore & Shepel, 1989), and adaptation to illness (Gottesman & Lewis, 1982; Mock, 1993; Tempelaar et al., 1989; Wolcott, Wellisch, Fawzy, & Landsverk, 1986). High self-esteem can serve as an indicator of positive well-being, mental health, and quality of life as well as positive adjustment or adaptation to illness. Similarly, low self-esteem can be an indicator that an individual is suffering from poor mental health and quality of life, and adjusting or adapting poorly to his/her illness experience.

Given the importance of self-esteem, one would expect to find a variety of self-esteem measures appropriate for use in a variety of populations. Although over 30 different self-esteem measures are available (Crandall, 1973; Wylie, 1989), many suffer from conceptual and methodological limitations. Many measures are composed of predetermined items with set response categories (Wylie, 1989) and therefore do not fit the conceptual definition of self-esteem as a subjective and multidimensional construct (Carpenter & Brockopp, 1994; Mohide et al., 1992; Pelham & Swann, 1989; Rosenberg, 1965). It is nearly impossible for scales with predetermined items to be sufficiently comprehensive to capture the multitude of variation in characteristics important to self-esteem. Because illness can affect each individual differently, capturing the subjective and multidimensional nature of self-esteem seems particularly important when assessing the impact of illness.

Other self-esteem measures not composed of predetermined items continue to be problematic since they do not fully address the qualitative component of self-esteem. Several measures of self-esteem are designed to allow the respondent to provide narrative descriptors of self-esteem (Wylie, 1989). However, when these measures are used, the focus remains one of obtaining a numerical self-esteem rating. Using complicated scoring methods, researchers assign a numerical rating to participants' narrative responses. The artificiality of assigning a numerical rating combined with loss of rich and valuable narrative data raises concerns about the usefulness of such measures. In particular, data on the individualized impact of illness may be lost in converting narrative data to numerical scores.

A third concern with existing self-esteem measures is that they do not fit with the idea that self-esteem fluctuates over time (Carpenter, 1996; Carpenter & Brockopp, 1994; Maslow, 1971). Self-esteem has been shown to fluctuate over time in response to illness and other life events (Carpenter, 1994; Frank-Stromberg & Wright, 1984; Lewis et al., 1979). However, several measures of self-esteem were designed by individuals grounded in the belief that self-esteem is stable over time

(Rosenberg, 1965; Wylie, 1989). Such measures are not likely to be sensitive to temporal fluctuations or changes in self-esteem since they were designed to measure stability in self-esteem. Using such measures among people who are ill may falsely create the belief that the illness experience has no impact on the individual, e.g., self-esteem does not fluctuate with illness.

CONCEPTUAL BASIS OF THE SELF-ANCHORING SELF-ESTEEM SCALE

To address limitations of existing measures, an alternative measure of self-esteem was created and called the Self-Anchoring Self-Esteem Scale (SASES). This alternate measure was based on two important conceptual points. First, self-esteem is a subjective and multidimensional concept (Carpenter & Brockopp, 1994; Mohide et al., 1992; Pelham & Swann, 1989; Rosenberg, 1965). Each individual holds thoughts and feelings specific to a personal self and only the individual is able to reveal these thoughts and feelings of self-esteem. Others are unable to accurately judge how another person thinks and feels about his/her own self. Self-esteem is multidimensional because it is a composite of numerous positive and negative thoughts and feelings evaluating physical, psychological, social and/or spiritual characteristics of the self (Curbow et al., 1990; Rosenberg, 1965, 1979; Wells & Marwell, 1976). Self-esteem is not based upon only one characteristic (swimming ability) or only one type of characteristic (physical), and instead is based upon a variety of self-characteristics (physical, psychological, social and/or spiritual).

The second point forming the conceptual basis for the SASES is that self-esteem can change over time and in relation to life events such as illness (Carpenter, 1996; Carpenter & Brockopp, 1994; Maslow, 1971). Self-esteem is not a static phenomenon because the self is not static. The self changes over time in relation to illness and other life events (Coward, 1990; Maslow, 1971). Thus, one's evaluation of the self, or self-esteem, is also likely to change over time. Self-esteem does not remain unchanged if changes in the self are experienced.

DESCRIPTION OF THE SELF-ANCHORING SELF-ESTEEM SCALE

The Self-Anchoring Self-Esteem Scale (SASES) is an adaptation of the Self-Anchoring Striving Scale (Cantril, 1965). The Self-Anchoring Scale is not composed of individual items and instead consists of a picture of a 10-step ladder anchored at the endpoints with phrases consistent with the construct being measured, e.g. high and low self-esteem. Self-anchoring refers to Cantril's methodology of requiring individuals to define the endpoints of the ladder prior to providing numerical ratings. The name was changed from striving, referring to the scale's original use to study quality of life, to self-esteem in keeping with the current construct under study.

Applying Cantril's (1965) methodology to study self-esteem results in a measure that is advantageous for several reasons. First, the SASES can be individualized and personalized, thus reflecting the subjective and multidimensional nature of self-esteem. For the SASES, individuals are shown a picture of a 10-point ladder and asked to provide descriptors to personalize the meaning of the high self-esteem endpoint (number 10) and low self-esteem endpoint (number 1) and then provide numerical ratings of self-esteem (see Figure 1). On the SASES, individuals are given the freedom to indicate any type of characteristic important to self-esteem. Participants are not required to respond to predetermined items that may or may not be of individual importance. Individuals are able to personalize the meaning of the scale's endpoints and describe self-esteem individually. However, because the number 10 reflects high self-esteem and the number 1 reflects low self-esteem regardless of how these endpoints are subjectively defined, numerical comparisons can be made across participants using this scale.

A second advantage of the SASES is its ability to elicit both numerical and narrative data on self-esteem. Defining the scale's endpoints allows an individual

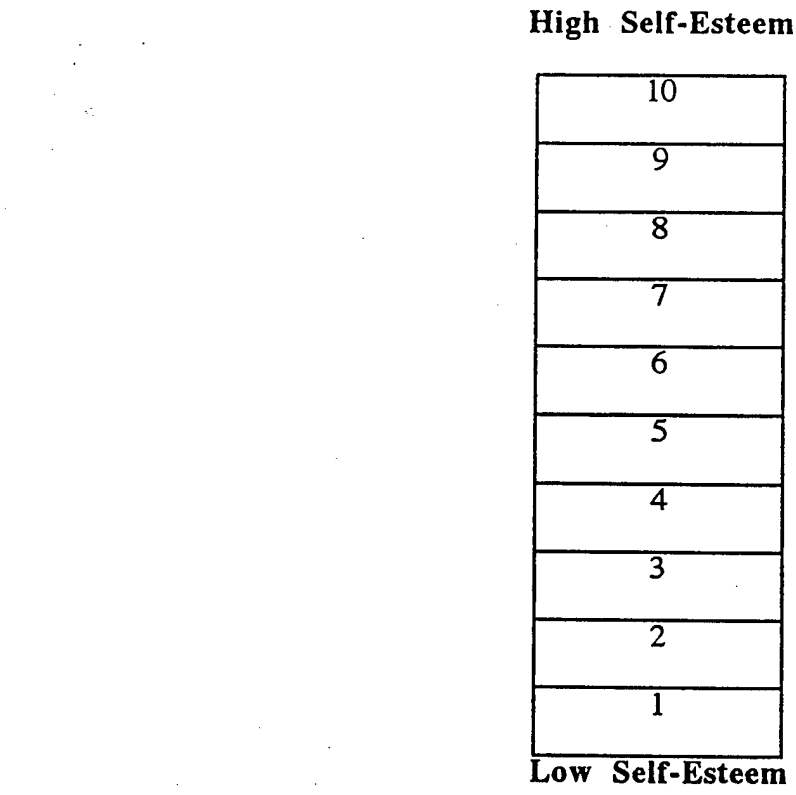

Figure 1. Self-Anchoring Self-Esteem Scale

to describe characteristics important to self-esteem and also allows for an increased understanding of numerical ratings. In defining the scale's endpoints, individuals are describing characteristics with which they are satisfied (high self-esteem) and characteristics with which they are dissatisfied (low self-esteem). For example, a participant might describe high self-esteem as "helping others, accomplishment, compassion for others, honesty" and describe low self-esteem as "doubting everything on earth, real pitfalls in my life" (Carpenter, 1996). Numerical ratings are then provided based on these narrative descriptions. Thus, narrative data describing the scale's endpoints are highly useful in understanding ratings provided by participants (Carpenter & Brockopp, 1994).

A third advantage of the SASES is that it may be more sensitive to temporal changes in self-esteem. This may be true for two reasons. First, the SASES fits with the theoretical idea that self-esteem can fluctuate over time (Carpenter, 1996; Maslow, 1965). Cantril's (1965) methodology involves requiring participants to rate the construct for the present (time of interview), past (retrospectively) and future (prospectively). By allowing individuals to rate present self-esteem in the context of past and future self-esteem, any type of temporal change can be noted—decreases, increases, or stability (Carpenter & Brockopp, 1994; Carpenter, 1996). In addition, because individuals can comparatively lower their past self-esteem ratings (past self-esteem lower than present self-esteem) to indicate an improvement in self-esteem occurring over time, a ceiling effect on the scale can be avoided.

Because individuals define the scale's endpoints in addition to providing numerical ratings, changes in ratings as well as changes in the meaning of the high and low esteem endpoints can be captured. By using Cantril's (1965) methodology, individuals are able to describe numerical changes in self-esteem as well as changes in characteristics important to high and/or low self-esteem. Because prior research has shown that temporal stability in numerical ratings does not necessarily equate to stability in descriptors of high and low self-esteem (Carpenter & Brockopp, 1994; Carpenter, 1996), eliciting numerical and narrative data may better capture temporal changes in self-esteem in comparison to eliciting numerical ratings alone.

ADMINISTRATION AND SCORING

Participants are shown a picture of a 10-step ladder and instructed the top of the ladder (number 10) corresponds to high self-esteem and the bottom of the ladder (number 1) corresponds to low self-esteem. The picture of the ladder includes the numbers 1 through 10 and the phrases high and low self-esteem. The ladder itself, with numbers placed between rungs, is identical to Cantril's (1965), except SASES numbers begin at one. The SASES does not include a zero based on the assumption that self-esteem can be low, but never zero or absent. Because the ladder ranges from 1 to 10, potential self-esteem scores also range from 1 to 10 with higher scores indicative of higher self-esteem.

Participants are asked to subjectively define the endpoints of the SASES using instructions modeled on Cantril's (1965) questions regarding life satisfaction and simply substituting phrases synonymous with self-esteem denoted by Rosenberg

(1965). In regard to the number 10, participants are instructed: "High self-esteem can mean that you respect yourself, accept yourself, and are satisfied with yourself. If you think about high self-esteem, what does this mean to you? What makes you, or would make you feel highly satisfied with yourself? Tell me what high self-esteem means to you." In regards to number 1, participants are instructed: "Low self-esteem can mean that you have little respect for yourself, reject yourself, and feel dissatisfied with yourself. If you think about low self-esteem, what does this mean to you? What makes you, or would make you feel dissatisfied with yourself? Tell me what low self-esteem means to you." As each participant defines the endpoints, key words and phrases can be written next to the high and low self-esteem endpoints or verbal responses can be tape-recorded, transcribed verbatim, and analyzed using qualitative data management techniques. Either method can be used to produce a listing of characteristics defining high and low self-esteem for each individual participant.

After defining the endpoints of the SASES, participants are asked to provide a numerical rating of self-esteem for the present (time of interview). Following Cantril's (1965) methodology, participants are also asked to provide ratings for past and future based on previously supplied descriptors. Numerical ratings are written at the bottom of the page in blanks next to the words past, present, and future. If change in self-esteem is of particular interest to an investigator (e.g.; increased or decreased self-esteem occurring following diagnosis of illness), participants can also be asked to describe the meaning of any numerical differences in scores (e.g.; describe reasons why self-esteem has increased or decreased following cancer). Thus, each participant's completed scale will include numerical ratings for past, present, and future as well as a listing of descriptors (either written during the interview or produced from transcripts).

PURPOSE

Data were pooled from three cross-sectional studies to explore psychometric properties of the SASES. The goals of this study were to examine test-retest reliability, two types of construct validity (convergent and known groups validation), criterion-related concurrent validity, and content validity of the scale.

METHODS

Samples and Settings

The three cross-sectional studies included in the analysis involved four samples. Two samples consisted of women with cancer and two samples consisted of individuals without cancer. The first sample consisted of 30 women with cancer receiving chemotherapy recruited from an outpatient oncology clinic or inpatient oncology unit (refer to Carpenter & Brockopp, 1994). Women were over age 18, receiving chemotherapy on the day of interview and experiencing hair loss due to

treatment. The second sample was a convenience sample of 47 Registered Nurses enrolled in a graduate level research course.

The third and fourth samples included 64 women postdiagnosis of breast cancer and 64 age-matched comparison women without cancer (refer to Carpenter, 1996). Women with breast cancer were aged 35 and older, at least 2 months posttreatment (surgery, radiation, chemotherapy), and not more than 54 months postdiagnosis. Comparison women were age-matched to within 4 years to a woman with breast cancer and had no prior diagnosis of breast or other cancer. Data from the 64 women with breast cancer were not combined with the 30 women with cancer due to differences in stage of treatment (completed treatment vs. actively receiving treatment).

Measures

Demographic Information. Demographic data were collected from each of the four samples, although the exact information collected varied slightly across studies. For the 30 women with cancer receiving chemotherapy (study 1), data were available for age, race, time since diagnosis, site of primary cancer, and type of chemotherapy received. For the graduate nursing students (study 2), demographic data collected included gender, age range, and education level. For the 64 women posttreatment for breast cancer and 64 comparison women in study 3, data were collected on age, race, marital status, education, and income. In addition, detailed disease and treatment information, such as age at diagnosis, stage and laterality of cancer, and types of therapies received, were gathered for the 64 women with breast cancer.

The Rosenberg Self-Esteem Scale. Participants in all four samples completed the Rosenberg Self-Esteem Scale, a 10-item scale designed to measure global self-esteem (Corcoran, 1987; Rosenberg, 1965). Participants responded to each item from strongly agree (1) to strongly disagree (4). Total scoring was performed by summing individual items after reverse scoring items 1, 3, 4, 7, 10. These items were reversed so that high scores indicated high self-esteem with total scores ranging from 10 to 40. Cronbach's alpha coefficients have been previously reported to range from 0.76 to 0.87 among samples of individuals diagnosed with cancer (Curbow & Somerfield, 1991). For this study, internal consistency of the Rosenberg scale was as follows: 30 women with cancer, $\alpha = 0.64$; graduate nursing students time 1, $\alpha = 0.43$; graduate nursing students time 2, $\alpha = 0.22$; 64 women with breast cancer, $\alpha = 0.87$; and 64 comparison women, $\alpha = 0.87$. Rosenberg scale scores were used to examine validity of the SASES.

RYFF'S SELF-ACCEPTANCE SCALE

Data for Ryff's Self-Acceptance Scale were available for the 64 women with breast cancer and 64 age-matched comparison women. The Self-Acceptance scale is a 14-

item scale measuring self-acceptance (C. D. Ryff, personal communication, November, 1994; Ryff, 1989); a concept considered synonymous with self-esteem (Rosenberg, 1965). Participants responded to each item from strongly disagree (1) to strongly agree (6). The scale is divided between positively and negatively worded items. To obtain a total score, negatively worded items are reversed and responses to all items are summed. High scores indicate high self-acceptance and total scores range from 14 to 84. Internal consistency for this scale was high ($\alpha =$ 0.89) among the 64 women with breast cancer and 64 aged-matched comparison. Construct validity of this scale has been supported since the self-acceptance scale correlated positively with positive measures of psychological adjustment and negatively with measures of distress (Ryff, 1989). Self-acceptance scores were used to examine validity of the SASES.

The Self-Anchoring Self-Esteem Scale (SASES). Participants in all four samples completed the SASES. After defining the endpoints of the SASES, all participants were asked to provide a numerical rating of self-esteem for the present (time of interview). Following Cantril's (1965) methodology, participants were also asked to provide ratings for future and past self-esteem. With the exception of the 30 women with cancer (study 1), participants were asked to rate self-esteem prospectively for 2 years in the future. All participants were also asked to provide retrospective ratings for past self-esteem. For the 30 women with cancer and 64 women with breast cancer, past was defined as the time immediately prior to diagnosis of cancer. For the students, past referred to 2 years prior. For the 64 comparison women, time in months for past self-esteem ratings was determined according to the date of diagnosis of their age-matched counterpart with breast cancer. For example, if a woman with breast cancer was 16 months postdiagnosis, her age-matched counterpart without cancer was asked to rate self-esteem retrospectively for 16 months prior.

PROCEDURES

Procedures varied slightly across the three studies and appropriate Institutional Review Board approval was obtained for all studies. Procedures followed for study 1 are detailed in Carpenter and Brockopp (1994). In study 1, the Rosenberg scale and SASES were completed during a single, personal, interview session. Participants' descriptions of high and low self-esteem endpoints on the SASES were recorded on paper by the investigator. Verbatim words or phrases used by the participant were written next to the scale's endpoints.

For study 2, students were approached by the investigator during scheduled class time as arranged with the course instructor on two different occasions. Students were invited to take part in the study and asked to complete the Rosenberg scale and SASES at an initial session and at a second session two weeks later. Because the SASES was administered while the students were assembled for class, individual interviews with the students did not occur and students were required to write rather than verbally discuss their descriptions for the high and low self-esteem endpoints.

Data from students were used to calculate two week test-retest reliabilities for the Rosenberg scale and SASES.

For study 3, women were recruited through newspaper advertisements, friends, and from a breast care clinic. Each of the 64 women with breast cancer and 64 comparison women participated in individual interviews with the investigator. Interviews were tape-recorded and transcribed verbatim to provide comprehensive narrative data for participants' descriptions of the high and low self-esteem endpoints on the SASES.

RESULTS

Demographic Characteristics of the Samples

Demographic characteristics of the 30 women with cancer are detailed in Carpenter and Brockopp (1994). Women were Caucasian, an average of 52.6 years old, less than 2 years post diagnosis, and receiving chemotherapy primarily as outpatients. Breast cancer was the most common diagnosis (37%), followed by ovarian (13%), lung (10%), liver (10%) and colon cancer (10%).

Of the pool of 47 graduate nursing students, complete data were available for 32 students. Attrition was related to students being absent from class at times 1 and/or 2, declining to participate, and/or failing to fill out both the SASES and Rosenberg scale. Of the 32 students with data for the Rosenberg scale and SASES at times 1 and 2 and who were included in the analysis, 87.5% were female and all had completed a BSN prior to enrolling in the research course. Age ranges of the students were varied; 18.8% were between 20 and 29 years old, 50% were in their 30's, 25% were between 40 and 49 years old, and the remaining 6.2% were in their 50's.

Among the 64 women with breast cancer and 64 matched comparison women, no differences were found between the groups on age, race, marital status, education, or income (Carpenter, 1996). Women were primarily Caucasian (96.1%) and married (40.6%), with 48.4% having completed a college degree, and with a mean household income per year of $37,500. Among the 64 women with breast cancer, 46.9% were stage 0 or I at diagnosis, 64.1% underwent mastectomy, and 65.6% underwent some type of adjuvant therapy (radiation and/or chemotherapy) in addition to their surgery. Mean time post diagnosis was 30.3 months ($SD = 15.1$, range 3 to 54). All women were between 2 and 54 months posttreatment ($M = 26.5$, $SD = 25.6$).

Descriptive Statistics

Descriptive statistics for all measures are listed in Table 1. The following pattern was noted in SASES ratings for each group of participants. Past ratings were lower than present ratings, which were lower than future ratings. The exception to this pattern was the group of 30 women with breast cancer whose present ratings were significantly lower than past ratings, $t(30) = 2.87$, $p < 0.01$.

TABLE 1. Means and Standard Deviations for Self-Esteem Measures

	Sample (*n*)				
	Study 1	Study 2		Study 3	
Measure*M*(*SD*)	Women with cancer (30)	Students time 1 (32)	Students time 2 (32)	Women with breast cancer (64)	Comparison women (64)
Rosenberg Self-Esteem Scale	29.5 (5.6)	33.5 (3.9)	33.4 (3.8)	35.1 (4.6)	34.1 (4.8)
Ryff's Self-Acceptance Scale	N/A	N/A	N/A	69.8 (10.4)	67.2 (11.1)
SASES—past	6.7 (2.2)	8.0 (1.3)	8.0 (1.2)	8.0 (1.5)	7.9 (1.5)
SASES—future	9.1 (1.3)	6.8 (1.6)	6.7 (1.7)	7.1 (2.3)	6.2 (2.3)
SASES—FUTURE	N/A	9.1 (0.7)	9.0 (0.8)	9.0 (1.0)	8.6 (1.4)

Note. For student's data, time 2 = 2 weeks later than time 1. SASES = Self-Anchoring Self-Esteem Scale. Present = time of interview, Past = retrospective rating prior to diagnosis for women with cancer (studies 1 and 3), time for comparison women (study 3) matched to time of diagnosis of their matched counterpart with cancer, and 2 years prior for students (study 2). Future = prospective rating for 2 years in the future. N/A = not assessed.

Test-Retest Reliability

Two-week test-retest reliabilities for the Rosenberg scale and SASES past, present and future ratings were assessed using correlation coefficients and data from the sample of 32 graduate nursing students (study 2). SASES test-retest reliabilities were comparable to those for the Rosenberg and correlations between scores at times 1 and 2 were high; (a) Rosenberg scale, $r = 0.87$; (b) SASES past, $r = 0.89$; (c) SASES present, $r = 0.92$; (d) SASES future, $r = 0.84$.

Test-retest reliability of the SASES was also examined at the individual level. Change in present self-esteem and change in Rosenberg scale scores from time 1 to time 2 was calculated by subtracting time 2 scores from time 1 scores for each individual. A frequency distribution was calculated and the number of participants whose time 1 to time 2 scores changed by 10% was determined. On the SASES, 10% change referred to a 1 point increase or decrease from time 1 to 2. On the Rosenberg scale, 10% referred to a 4-point increase or decrease from time 1 to 2. A total of 3 participants (9.4%) had a 10% discrepancy between time 1 and time 2 on the Rosenberg scale, while a total of 7 participants (21.9%) had a 10% discrepancy from time 1 to 2 on the SASES. No individual's ratings changed more than 10% from time 1 to time 2.

Content Validity

To examine content validity, narrative descriptors of high and low self-esteem were analyzed using a three-step process outlined by Miles and Huberman (1994). Data were reduced, visually displayed and compared across individuals, and conclusions were drawn and verified through the use of a second rater/coder. Data for the 64 women with breast cancer were also verified using a focus group of study participants ($n = 5$).

The 30 women with cancer described self-esteem in terms of characteristics that had been negatively and/or positively affected by cancer diagnosis and treatment (refer to Carpenter & Brockopp, 1994). Descriptors of self-esteem reflected four categories: physical, psychological, social, and spiritual characteristics. Women were able to provide a variety of descriptors in each category to define the scale's endpoints and thus described self-esteem as a subjective and multidimensional construct. In addition, women were able to successfully personalize the scale to describe self-esteem as it was affected by their own illness experiences.

Similar categories developed from students' data, although students' narrative responses emphasized achievement and success. Descriptors which clustered around the importance of work were prominent and related to the importance of setting a goal, striving for a goal, and reaching a goal. Achievement may have been particularly important to this group of individuals since they were in the midst of completing graduate education at the time of interview. Data from this group supported the scale's ability to capture self-esteem as an evaluation of physical, psychological, social and spiritual characteristics and as a subjective and multidimensional construct.

Comparing narrative data between the 64 women with breast cancer and their age-matched counterparts revealed striking differences between groups despite similarity in numerical self-esteem (Carpenter, 1996). Group differences were found in relation to the types of characteristics important to self-esteem. Analysis supported the construct of self-esteem as composed of both numerical and narrative components and revealed important information about the impact of breast cancer on a woman's self-esteem.

Construct Validity

Correlations between the Rosenberg scale and SASES and self-acceptance scale and SASES were used to examine convergent validity; one type of construct validity (Devellis, 1991) (see Table 2). SASES present ratings, rather than past or future ratings, were used so that correlations reflected relationships between

TABLE 2. Pearson Correlations Between Measures

	Sample (*n*)				
	Study 1	Study 2		Study 3	
Measures	Women with cancer (30)	Students time 1 (32)	Students time 2 (32)	Women with breast cancer (64)	Comparison women (64)
SASES and Rosenberg's Self-Esteem Scale	0.48	0.65	0.58	0.75	0.70
SASES and Ryff's Self-Acceptance Scale	N/A	N/A	N/A	0.64	0.76

Note. High scores on all measures indicate high self-esteem. SASES = Self-anchoring self-esteem scale ratings at time of interview. N/A = data for self-acceptance scale not available. All correlations $p < 0.01$.

measures at time of interview. Positive correlations were expected since high scores on all measures reflected high self-esteem or high self-acceptance. Correlation between the SASES and Rosenberg scale among the 30 women with cancer was relatively low ($r = 0.48$) in comparison to correlations computed for the remaining samples which ranged from 0.58 to 0.75.

Known groups validation, or the ability of the SASES to capture high and low self-esteem groups, was the second method used to examine construct validity. A two-step procedure was employed. First, cutoff scores for high and low self-esteem on the Rosenberg scale were determined based on recommendations in previous research (Gottesman, 1982; Neuling & Winefield, 1988). For this study, a score of 30 was used as the cutoff for high self-esteem. Participants with a total Rosenberg scale score under 30 were classified into a low self-esteem group. Second, the number of participants with low self-esteem on the SASES was determined using a cutoff score of 6 (Cantril, 1965). Participants with SASES present ratings of 6 or less were classified as low self-esteem. The number of participants from each sample grouped as having low self-esteem on the Rosenberg scale and on the SASES were compared (see Table 3). The SASES was comparable to the Rosenberg scale in differentiating between high and low self-esteem groups.

Criterion-Related (Concurrent) Validity

To examine concurrent validity of the SASES, one aspect of criterion-related validity (Devellis, 1991), correlations between SASES present ratings and individual Rosenberg scale and self-acceptance scale items were calculated for each sample of participants. Because the 64 women with breast cancer and 64 comparison women were matched on age and similar on demographics, z-tests of differences were used to determine if correlations were significantly different between these two groups.

Correlations between SASES present ratings and individual Rosenberg scale items were examined first (see Table 4). SASES present ratings were highly correlated with Rosenberg scale item 1, indicating that the SASES adequately

TABLE 3. Number of Participants Classified into Low Self-Esteem Group Using Total Scores on the Rosenberg Self-Esteem Scale and Present Ratings on the Self-Anchoring Self-Esteem Scale

	Sample (n)				
	Study 1	Study 2		Study 3	
SCALE (low self-esteem)	Women with cancer (30)	Students time 1 (32)	Students time 2 (32)	Women with breast cancer (64)	Comparison women (64)
Rosenberg Self-Esteem Scale (total score < 30)	13 (43.4%)	3 (9.4%)	4 (12.5%)	7 (10.9%)	13 (20.3%)
Self-Anchoring Self-Esteem Scale (present rating ≤ 6)	12 (40%)	3 (9.4%)	3 (9.4%)	8 (12.5%)	8 (12.5%)

TABLE 4. Pearson Correlations Between SASES Ratings at Time of Interview and Rosenberg Self-Esteem Scale Items

	Sample (*n*)				
	Study 1	Study 2		Study 3	
Rosenberg item	Women with cancer (30)	Students time 1 (32)	Students time 2 (32)	Women with breast cancer (64)	Comparison women (64)
1. On the whole, I am satisfied with myself.	–0.78**	–0.68**	–0.53**	–063**	–0.71**
2. At times, I think I am no good at all.	0.19	0.32	0.38*	0.58**	0.31**
3. I feel that I have a number of good qualities.	–0.16	–0.32	–0.13	–0.39**	–0.36**
4. I am unable to do things as well as most people.	–0.13	–0.45**	–0.50*	–0.37**	–0.38**
5. I feel I do not have much to be proud of.	0.46**	0.30**	0.06	0.50**	–0.59**
6. I certainly feel useless at times.	0.06	0.28	0.32	0.49**	0.39**
7. I feel that I'm a person of worth, at least on an equal plane with others.	–0.11	–0.38*	–0.28	–0.56**	–0.44**
8. I wish I could have more respect for myself	0.23	0.52**	0.61**	0.54**	0.53**
9. All in all, I am inclined to feel that I am a failure.	0.63**	0.45**	0.39*	0.49**	0.53**
10. I take a positive attitude toward myself	–0.35	–0.39*	–0.30	–0.65**	–0.66**

Note. Rosenberg scale items 2, 5, 6, 8, and 9 high scores = high self-esteem. Rosenberg items 1, 3, 4, 7, and 10 high scores = low self-esteem. Self-Anchoring ratings high scores = high self-esteem.
*$p < 0.05$, **$p < 0.01$.

captured the aspect of self-esteem related to satisfaction with the self (Rosenberg, 1965). Correlations between SASES present ratings and Rosenberg item 1 (see Table 4) equaled or exceeded correlations between SASES present ratings and Rosenberg total scores (see Table 3). In comparing correlations between age-matched participants from study 3, none of the correlations between SASES present ratings and individual Rosenberg items were significantly different between the groups based on z-tests of differences (all p's > 0.05).

Correlations between SASES present ratings and individual self-acceptance scale items were examined next (see Table 5). Recall that only participants from study 3 completed the RSAS. Among the 64 women with breast cancer, SASES present ratings were most highly correlated with items 10 and 14. Both items were inversely related to SASES present ratings due to their negative wording. No single self-acceptance item correlated significantly with SASES present ratings, *r*s(64) = 0.11 to 0.58, as highly as the self-acceptance total score correlated with SASES present ratings, *r*(64) = 0.64, among the women with breast cancer.

Among the 64 comparison women, SASES present ratings were most highly correlated with self-acceptance scale items 1, 2, and 13. Correlation between item

TABLE 5. Comparing Pearson Correlations Between SASES[a] and RSAS[b] Items Among Women With Breast Cancer and Age-Matched Comparison Women Using Z-Tests of Differences

Content of self-acceptance scale items	Sample (n) Study 3		
	Women with Breast Cancer (64)	Comparison Women (64)	Z-tests of Differences
1. Pleased with story of my life	0.50	0.67	
2. Feel confident and positive about self	0.52	0.81	–3.04
3. Feel others have gotten more out of life	–0.49	–0.22 *ns*	
4. Many things about self I would change	–0.37	–0.50	
5. Like most aspects of my personality	0.47	0.43	
6. Everything has worked out for best	0.32	0.45	
7. Feel disappointed about achievements	–0.26	–0.53	
8. Proud of life I lead	0.48	0.42	
9. Envy others for lives they lead	–0.36	–0.34	
10. Attitude about self not positive	–0.58	–0.50	
11 Feel discouraged about ways lived life	–0.46	–0.49	
12 Wouldn't want to change past	0.11 *ns*	0.45	–2.09
13 Feel good about who I am	0.34	0.67	–2.48
14 Have more than my share of weaknesses	–0.58	–0.48	

Note. All correlations significant, $p < 0.05$ unless noted. Zs listed for $p < 0.05$.
[a]Self-Anchoring Self-Esteem Scale present ratings, time of interview, high scores indicate high self-esteem.
[b]Ryff's Self-Acceptance Scale, time of interview, items 3, 4, 7, 9, 10, 11, 14, low scores indicate high self-acceptance.

two and SASES present ratings, $r(64) = 0.81$, was higher than correlation between self-acceptance total scores and SASES ratings, $r(64) = 0.76$. Using z-tests of differences, correlations between SASES ratings and self-acceptance scale items 2, 12, and 13 were significantly lower among the women with breast cancer in comparison to their age-matched counterparts without cancer ($p < 0.05$).

Qualitative data defining the endpoints of high and low self-esteem were used to interpret Rosenberg scale and self-acceptance scale items correlating poorly with SASES present ratings. For example, Rosenberg items 2 and 6 which reflect abilities were poorly correlated with SASES present ratings among the 30 women with cancer receiving chemotherapy, but moderately correlated for the remaining samples. On the Rosenberg scale, agreeing that one is no good (item 2) or feels useless (item 6) results in a set decrease in one's total rating. The subjective importance of feeling no good or useless is not accounted for on the Rosenberg scale. In contrast, on the SASES, women were able to identify that feeling no good or useless were major causes of low self-esteem related to chemotherapy-induced fatigue. Women were able to assign more subjective importance to loss of abilities on the SASES than on the Rosenberg scale by adjusting their present self-esteem ratings in accordance with the loss. As a result, SASES ratings correlated poorly with Rosenberg items 2 and 6.

Similarly on the RSAS, item 12 which read, "The past had its ups and downs, but in general, I wouldn't want to change it," had essentially no relationship with SASES ratings among the 64 women with breast cancer. Some women verbalized

wanting to change the past in terms of being diagnosed with cancer while others felt an acceptance of their diagnosis. Individual differences in the meaning of this item among the women with breast cancer may have contributed to low item to SASES total correlations.

DISCUSSION

Psychometric data for the SASES have not been previously published apart from estimates of construct validity reported in Carpenter and Brockopp (1994). Findings described in this research support two-week test-retest reliability, two types of construct validity (convergent and known groups validation), criterion related-concurrent validity, and content validity of the SASES as a measure of self-esteem.

Test-retest reliability for past, present, and future ratings of self-esteem was supported by high correlations between students' data at times 1 and 2. Stability of past and future ratings was comparable to present ratings during the test-retest assessment, indicating that including retrospective past and prospective future ratings is appropriate. Although correlations indicated that test-retest reliability of the SASES was high, examination of individual responses suggests the SASES may be slightly more sensitive to temporal changes in self-esteem as compared than the Rosenberg scale. Specifically, the percentage of individuals whose ratings changed a significant amount from time 1 to time 2 on the SASES (21.9%) was double the percentage of individuals whose ratings changed on the Rosenberg scale (9.4%). Although the ability to capture changes in self-esteem over time is equated with lower reliability, lower reliability over time is expected in an instrument measuring fluctuations rather than stability in self-esteem ratings. The superior ability of the SASES to capture temporal changes may be related to success in capturing the subjective nature of self-esteem.

Validity estimates suggest that while the Rosenberg scale may be a useful measure in a relatively healthy population, it may not be sensitive to the acute impact of cancer or other illnesses. Examining construct and criterion related validity estimates revealed several differences between the Rosenberg scale and SASES. First, based on convergent (construct) validity, correlations between Rosenberg total and SASES present ratings were lowest among the 30 women with cancer experiencing specific chemotherapy-related side effects. Among these women, the Rosenberg scale did not seem to capture the individual and personalized impact of cancer to the same extent as the SASES. This point was supported by narrative data which illustrated a wide variation in characteristics important to self-esteem among each sample.

Second, known groups validation procedures indicated that the SASES was comparable to the Rosenberg scale in classifying individuals into high and low self-esteem groups. However, the Rosenberg scale was not useful in identifying individuals with lowered, but not necessarily low, self-esteem. While the Rosenberg scale can differentiate between individuals with high and low self-esteem, it does not reveal information about individuals considered to have high self-esteem, but

whose self-esteem has decreased in response to illness. In contrast, Cantril's (1965) methodology is useful in identifying a lowering of self-esteem among individuals whose self-esteem remains high following diagnosis of an illness. For example, a woman whose self-esteem decreased from 10 prediagnosis to 7 postdiagnosis could be grouped with high self-esteem individuals even though she indicated that self-esteem was lowered by 3 points postdiagnosis. Assessing present ratings in the context of past and future ratings was useful in capturing a lowering of self-esteem occurring postdiagnosis.

Third, examination of concurrent (criterion-related) validity showed that individual, predetermined Rosenberg items were more poorly correlated with SASES present ratings among the women with cancer receiving chemotherapy than the other samples. Among the women receiving chemotherapy, 5 of the 10 items (50%) correlated below $r = 0.20$ with SASES present ratings. In the remaining samples, the majority of correlations between Rosenberg items and SASES ratings exceeded $r = 0.20$. The content of the Rosenberg scale items did not seem to reflect concerns of women receiving chemotherapy that were revealed during qualitative data analysis. In addition, Rosenberg scale items are equally weighted during total scoring whereas SASES ratings are not based on equally weighted predetermined items. Profound agreement or disagreement with one or two Rosenberg items does not significantly affect total scores. In contrast, because of the personalized nature of the SASES, one or two descriptors of high or low self-esteem may be used to indicate significantly increased or decreased self-esteem. Unlike the Rosenberg scale, on the SASES individuals can indicate one or more changes in self-esteem related to illness that have had a profound impact on self-esteem.

Narrative data provided by participant's supported content validity of the SASES as a measure of self-esteem. Questions modeled on Rosenberg's (1965) definition of self-esteem provided a sound basis for participants to describe self-esteem, while Cantril's (1965) methodology provided the freedom necessary for participants to vary in their descriptions of self-esteem. On a practical note, narrative data provided by participants were richer and provided a deeper level of understanding when elicited on an individual basis during interviews. Data from students, which were elicited using written instructions, emerged as short phrases or single word descriptors. Gaining data using written instructions did not allow for clarification of responses by the investigator. In a few cases, the exact meaning of a word describing high self-esteem could have been better understood if the scale had been used during an individual interview session. However, both methods were useful in obtaining narrative descriptors of high and low self-esteem.

In addition to being a psychometrically sound and advantageous measure of self-esteem, several aspects of the SASES make it highly useful for nurses to use in clinical practice or research. First, the simplicity of the scale makes it highly portable and easily replicated. A copy of the ladder with numbers 1 to 10 and high and low self-esteem written next to the endpoints can be easily reproduced using only paper and pencil. Second, because it is based on a numeric rating scale rather than a visual analog scale, no scoring or measuring is involved. Nurses do not need to carry a ruler for measuring an individual's rating as is done for a visual analog

scale. Third, descriptors provided by participants can be used to develop individualized nursing interventions or research interventions. An individual's descriptors contain information about the personal meaning of high and low self-esteem, including the impact that an illness may have had. Using data elicited with the SASES, nurses can assess the impact of illness on an individual's self-esteem and tailor nursing care or design research interventions to promote positive feelings about the self throughout the trajectory of the illness experience.

SUMMARY AND CONCLUSIONS

Application of Cantril's (1965) methodology to the study of self-esteem was described in this research. Advantages of the SASES over existing measures of self-esteem were supported in relation to the scale's ability to (a) capture the individualized impact of illness, such as cancer, (b) account for both numerical and narrative components of self-esteem and (c) capture temporal changes in self-esteem. Psychometric properties of the scale were supported among four samples. The SASES appears to be an advantageous, reliable and valid measure of self-esteem among women receiving treatment for cancer, women posttreatment for cancer, and individuals without a history of cancer. A careful evaluation of the SASES in low-income and minority samples is recommended for future development.

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Hereditary Cancer Risk Notification and Testing: How Interested Is the General Population?

By Michael A. Andrykowski, Robin Lightner, Jamie L. Studts, and Rita K. Munn

Purpose: Great interest in predictive testing for hereditary cancer syndromes has been reported. Prior research has focused on testing for specific hereditary syndromes and/or among individuals at high risk for positive carrier status. Given anticipated expansion of both the range of hereditary syndromes for which testing will be available, as well as the clinical settings in which testing will occur, assessment of interest in hereditary cancer risk testing and notification in the general public is warranted.

Methods: As part of an annual statewide telephone survey, adults' (N = 654) interest in hereditary cancer risk testing and notification was assessed.

Results: Interest in both risk testing (82%) and risk notification (87%) was high. Logistic regression analyses indicated that disinterest in risk notification was associated with female sex, performance of fewer health protective behaviors, and better perceptions of personal health. Disinterest in risk testing was associated with these same variables as well as older age, less concern over developing cancer, and a more extensive history of cancer in first degree relatives.

Conclusion: In the absence of risk-reducing behaviors with demonstrable efficacy, hereditary risk testing programs may have difficulty attracting the interest of those at greatest risk for carrier status. In contrast, many individuals at low risk for positive carrier status might seek testing, perhaps as a means of seeking reassurance regarding their low hereditary risk.

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A VARIETY OF CANCER susceptibility genes have been identified.[1] Mutations in these genes are linked to a spectrum of hereditary cancer syndromes, including breast and ovarian cancer,[2,3] breast cancer,[4] colon cancer,[5] familial adenomatous polyposis,[6] hereditary retinoblastoma,[7] pancreatic cancer and melanoma,[8] multiple endocrine neoplasia,[9] and Li-Fraumeni syndrome.[10] In some instances, most notably with regard to the BRCA1 gene, localization and cloning of the gene mutation has led to a laboratory test that permits identification of individuals who carry this gene.[11] Identification and location of additional cancer susceptibility genes and development of clinical tests to identify carriers of these genes can be anticipated. Although testing for hereditary cancer syndromes is now available only in the context of clinical research protocols, greater dissemination of this technology is likely. The goals of risk notification and testing are to increase appropriate cancer prevention and early detection behaviors; however, the benefits of risk testing have not been established. In addition, there are risks associated with testing.[12,13] Hence, identification of the extent of interest in risk notification and testing and factors that might motivate or dissuade use of these services are significant public health issues.

To date, the majority of studies have focused on specific cancer syndromes, including colorectal cancer,[14-16] breast cancer,[17-20] ovarian cancer,[21] and breast-ovarian cancer syndrome.[22] These studies have assessed interest in risk notification and testing in specific populations, including first-degree relatives (FDRs) of cancer patients,[15,20,21] college students,[19] women who attend mammography or gynecologic clinics,[18] and members of families in which the BRCA1 gene mutation has been identified.[22] Interest in the general population has been infrequently evaluated,[14,16,17] as has interest in risk testing for cancer in general.[17] In general, interest in risk notification and testing is high, with more than 80% of respondents indicating interest. Greater interest in risk testing has been positively associated with perceived cancer risk,[14,16,20,22] cancer-related worry,[14,20] perceived likelihood of carrying a cancer-susceptibility gene,[20] mood disturbance,[20] performance of health-protective behaviors,[17] regular clinical breast examinations,[18] and beliefs that mammography is effective in the early detection of breast cancer and that early-stage breast cancer is curable.[19] Although sociodemographic correlates of interest in risk notification and testing have been examined, few consistent relationships have emerged. Education was positively linked to interest in risk testing in FDRs of ovarian cancer patients[20] and interest in risk notification in a general population survey.[17] However, among individuals with a family history of colon cancer, education was negatively associated with interest in risk testing.[15] Additional variables associated with interest in risk testing include higher income,[16] younger age,[20] female sex,[22] and possession of private health insurance.[17] Finally,

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minority women were less interested in learning that they possessed a hereditary susceptibility to breast cancer than were nonminority women.[17]

This study examines the extent and correlates of interest in hereditary cancer risk notification and testing in a statewide sample of adults. Separate assessments of interest in risk testing and risk notification were obtained, because current testing protocols divide the testing process into discrete steps involving first risk testing and then risk notification.[11,23] It is assumed that each step requires a separate decision to proceed, with different factors potentially influencing this decision at each step. In addition to variables examined in prior research, we examined both awareness of the topic of hereditary cancer risk and perceptions of physical health as potential correlates of interest in risk testing and notification. Theory regarding the psychologic stages leading to adoption of health-promoting behavior suggests that less awareness would be associated with less interest in risk notification and testing.[24] Furthermore, the difficulties often encountered in convincing healthy, asymptomatic individuals to consider future health risks and adopt health-sustaining behaviors[25,26] suggest that adults in good physical health may be less interested in risk notification and testing.

METHODS

Procedure

Data were obtained from telephone interviews completed during September 1995, as part of an annual health survey of Kentucky residents. The survey was conducted by the Survey Research Center at the University of Kentucky. The Survey Research Center is a University-based center with expertise in survey design and administration, and extensive experience in statewide, regional, and national surveys for University faculty, state government, and federal agencies. The survey protocol used computer-assisted telephone interviewing. Quality control procedures included telephone monitoring, supervisor follow-up verification, postinterview coding and editing, and consistency check analysis of all final data files. Each residential telephone line in Kentucky had an equal chance of being called by the random-digit dialing procedure. The first respondent in the household older than 18 years of age was questioned.

A total of 1,322 residential telephone numbers were called. Refusals to participate or incomplete interviews resulted from 525 calls, while 143 respondents were ineligible (eg, deaf, too ill, unavailable after repeated calls, etc). A total of 654 calls resulted in complete interviews. This was 55.4% of telephone calls to eligible households (654 of 1,179).

Survey Questions

Responses to several clusters of questions included in the complete telephone interview were examined. In order of appearance in the interview, the clusters of questions included the following: health care system access and utilization, mental health, general health perceptions, protective health behaviors, cancer and hereditary risk, and personal and family history of cancer. Responses to questions regarding demographic information such as race, age, education, marital status, and current household income were also examined. These demographic questions were spaced throughout the interview.

Health care system access and utilization. The following three questions were used: (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? Responses to the latter two questions were used to categorize respondents as either having private insurance, public insurance, or no health insurance.

Mental health. Mental health was assessed using the five-item mental health subscale from the Medical Outcome Study Short Form Health Survey (MOS-20[27]). All questions use six-point Likert scales with responses ranging from "all of the time" to "none of the time." High scores indicate better mental health during the past month. Internal consistency, indexed by coefficient alpha, was .87 for the mental health scale.

General health perceptions. Perceptions of general health were assessed by the following four items: (1) I am somewhat ill; (2) I am as healthy as anybody I know; (3) My health is excellent; and (4) I have been feeling bad lately. Respondents indicated extent of agreement with each item using a five-point Likert scale with response alternatives ranging from "definitely true" to "definitely false." Negatively worded items were reverse-scored. Scores for the four items were then summed to create a general health perception score. Health perception scores ranged from 4 to 20, with higher scores indicative of more positive health perceptions. Internal consistency for health perception scores, as indexed by coefficient alpha, was .90.

Protective health behaviors. The following three questions assessed performance of protective health behaviors: (1) How often do you go to the dentist? (response options included: more frequently than every 6 months, every 6 months, every 12 months, every 2 to 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 options included: always, nearly always, sometimes, seldom, or never); and (3) Do you smoke cigarettes now? Responses to these three questions were classed as either health protective or not. Emphasis was on differentiating those clearly showing poor health-protective behavior from those showing more appropriate behaviors. Specifically, reports of no current smoking of cigarettes were classed as health-protective. Responses to the dental visitation question that indicated regular dental visits (ie, every 2 to 3 years or more frequently *v* only when need arises or not at all) were classed as health-protective. Responses to the seat belt question that indicated regular use (always or nearly always *v* sometimes, seldom, or never) were classed as health-protective. A composite health behavior index was computed for each respondent by summing the number of appropriate health-protective behaviors reported. Health behavior scores thus ranged from 0 to 3.

Cancer and hereditary risk. Seven questions were used. One question assessed respondents' concern that they will develop cancer in their lifetime. Responses were made on a four-point Likert scale that ranged from "very concerned" to "not at all concerned." Two questions assessed awareness of recent developments regarding hereditary risk for cancer. The first question was "Scientists now believe that some people inherit a gene from their parents that makes it very likely that they will develop breast, colon, or ovarian cancer sometime in their life. Have you heard or read about this theory before today?" Respondents who indicated that they had heard of this were then asked "Have you heard a lot or just a little about this theory?" Responses to these two questions were used to categorize

respondents into the following three groups: those who had not previously heard about hereditary risk for cancer, those who had heard a little, and those who had heard a lot.

Three questions assessed interest in being informed if they possessed a hereditary predisposition to develop cancer (ie, hereditary risk notification) and interest in undergoing a blood test to determine hereditary cancer risk (ie, hereditary risk testing). The first question was "Suppose you had inherited something from your parents that would make you more likely to develop cancer than most people; would you want to be told this?" Respondents answered yes or no. The second question was "Scientists are working on a blood test that could tell if a person had inherited a gene from their parents that would make them more likely than most people to develop cancer. If the blood test was inexpensive and easy to perform, do you think you would have the test performed?" Respondents answered yes or no. Those who indicated no interest in undergoing a blood test were asked the main reason for not being interested. Responses were recorded verbatim by the interviewer. A final question assessed respondents' perceptions of the likelihood that they personally were at elevated hereditary risk for cancer: "Do you think that you have inherited a gene from your parents that increases your chances of developing cancer?" Four response options were used: very likely, somewhat likely, somewhat unlikely, and very unlikely.

Personal and family history of cancer. Respondents were asked the following: "Has an immediate member of your family or a very close friend of yours ever been diagnosed with cancer?" Respondents answered yes or no. If they answered yes, a series of follow-up questions was asked to identify specific categories of relatives (eg, mother, father, sister, brother, grandparent, child, etc) with a history of cancer. An index of extent of cancer in FDRs was created by summing the number of categories of FDRs (ie, mother, father, sister, brother) with a positive history of cancer. Scores thus ranged from 0 (ie, no FDRs) to 4 (family history of cancer in mother, father, sister, and brother). Finally, respondents were asked "Have you ever been diagnosed with any type of cancer?" Those who answered yes then indicated the specific type of cancer with which they had been diagnosed.

Data Analysis

Data were analyzed using the Statistical Program for the Social Sciences-X (SPSS-X, SPSS Inc., Chicago, IL). All two-by-two χ^2 analyses used Yates correction. An alpha level of .05 was used as the criterion for statistical significance.

RESULTS

Sample Characteristics

Of 654 respondents, 56 (8.6%) reported that they had been diagnosed with cancer. These individuals were excluded from all study analyses. The final sample thus consisted of 598 respondents (42% male, 58% female) with a mean age of 45.5 years (SD, 15.8; range, 18 to 92). The sample was primarily white (94%), with black (4.3%) or other minority (1.7%) respondents comprising 6% of the sample. Educational status was as follows: grade school (6%), some high school (11%), high school graduate (38%), some college (28%), college graduate (10%), and postbaccalaureate study or degree (7%).

Table 1. Frequency of Responses to Various Survey Questions (N = 598)

Question/Response	% of Sample	95% Confidence Interval (%)
Concern over developing cancer during lifetime?		
Very concerned	25	22-28
Somewhat concerned	44	40-48
Not very concerned	18	15-21
Not at all concerned	13	10-16
Aware of topic of hereditary cancer risk?		
Not at all	18	15-21
A little	40	36-44
A lot	42	38-46
How likely that you inherited a cancer gene?		
Very likely	11	8-14
Somewhat likely	13	10-16
Somewhat unlikely	27	23-31
Very unlikely	38	34-42
Do not know	11	8-14
Want to be told if inherited cancer predisposition?		
Yes	87	84-90
No	8	6-10
Do not know	5	3-7
Likely to have easy, inexpensive blood test to determine hereditary cancer risk?		
Yes	82	79-85
No	12	9-15
Do not know	6	4-8

Comparison of respondents with 1990 United States Census data[28] suggests that the sample was representative of Kentucky residents with regard to proportion of minority respondents (6% in our sample *v* 8% in the state). The proportion of respondents with high school degrees (83%) or 4-year college degrees (19%) exceeded proportions in the state (65% and 14%, respectively). This is not surprising given the large proportion of Kentucky households with no telephone (10.2%),[29] most of which are low socioeconomic status households.

Cancer Concern

Respondents varied regarding concern that they would develop cancer in their lifetime (Table 1). The majority of respondents were either very (25%) or somewhat (44%) concerned, while only 18% indicated that they were not very concerned and 13% were not at all concerned.

Awareness of Topic of Hereditary Cancer Risk

Expressed awareness of the link between genetics and personal cancer risk also varied. While only a minority

of respondents (18%) had not heard or read anything about hereditary cancer risk, 40% of respondents had only heard or read a little. The remaining 42% of respondents reported that they had heard or read a lot regarding hereditary cancer risk.

Perceived Personal Likelihood of Possessing a Hereditary Cancer Risk

Respondents varied with regard to perceptions of how likely it was that they possessed a hereditary risk for cancer. Most respondents indicated that it was very unlikely (38%) or somewhat unlikely (27%). In contrast, 11% of respondents indicated that they believed it was very likely, while 13% indicated that they believed it was somewhat likely. The remaining 11% of respondents were uncertain regarding personal hereditary cancer risk.

Interest in Hereditary Cancer Risk Notification and Testing

Expressed interest in being informed if they possessed a hereditary predisposition for cancer was high: 87% of respondents indicated that they would like to be told if they possessed such a predisposition. Only 8% of respondents indicated that they would not be interested in knowing this information, while an additional 5% of respondents reported that they did not know what they would desire under the circumstances.

The reported likelihood that an individual would undergo an easy and inexpensive blood test to determine their hereditary cancer risk was also high. The majority of respondents (82%) indicated that it was likely they would undergo such testing. An additional 12% of respondents indicated that it was not likely they would undergo such testing, with the remaining 6% uncertain of what they would do. Reasons given by respondents (N = 69) who were not interested in undergoing a blood test to determine hereditary risk included "not worried about it" (n = 40), no family history of cancer (n = 9), lack of confidence in the testing (n = 6), dislike of needles (n = 5), not having time (n = 4), being too old (n = 3), and cost (n = 1). Fear of loss of insurance was infrequently cited (n = 1) as a reason for not undergoing hereditary cancer risk testing.

Comparison of responses to the two separate questions regarding interest in risk notification and risk testing indicated that most respondents were either interested in both notification and testing (85%) or not interested in either (5%). The remaining respondents expressed an interest in risk notification but were not interested in risk testing (7%), or expressed disinterest in risk notification but an interest in risk testing (3%).

Table 2. Relationship Between Interest in Hereditary Cancer Risk Notification and Testing and Demographic, Health Care Access, and Protective Health Behavior Variables

Variable	Risk Notification		Risk Testing	
	% Not Interested	No.	% Not Interested	No.
Demographic				
Race				
White	9	47/545	13	70/531
Nonwhite	13	4/32	10	3/30
Education				
< High school degree	13	12/95	12	11/89
≥ High school degree	8	39/473	13	62/473
Sex				
Male	7	18/243	10	23/241*
Female	10	33/326	16	50/322
Household income				
< $15,000	13	16/124	15	18/124
$15,000-$50,000	9	19/213	10	22/213
> $50,000	5	7/140	14	19/140
Health care access				
Have regular doctor				
Yes	9	43/501	13	64/495
No	12	8/68	13	9/68
Private health insurance				
Yes	8	29/381	11	40/373†
No	11	21/184	17	32/186
Protective health behaviors				
Health behavior scores				
0	21	4/19†	33	7/21*
1	18	18/102	13	12/96
2	7	15/207	14	29/205
3	6	14/240	10	25/240

*$P < .05$ (χ^2 test).
†$P < .01$ (χ^2 test).

Univariate Predictors of Interest in Risk Notification and Testing

Demographic characteristics. Relationships between race, education, sex, and annual household income and interest in hereditary cancer risk notification and testing were examined using χ^2 analyses (Table 2). Only sex was significantly associated with interest in risk testing (χ^2 [1] = 4.37; $P < .05$). Female respondents expressed greater disinterest (16%) in undergoing testing than males (10%). The relationship between interest in risk notification and income (χ^2 [2] = 5.12; $P = .08$) was marginally significant, with less income associated with less interest in risk notification.

Relationships between age and interest in risk notification and testing were examined using point-biserial corre-

Table 3. Relationship Between Interest in Hereditary Cancer Risk Notification and Testing and Cancer Concern, Awareness of Relation Between Genes and Cancer, and Likelihood of Possessing a Personal Hereditary Cancer Risk

Variable	Risk Notification		Risk Testing	
	% Not Interested	No.	% Not Interested	No.
Concerned about developing cancer during lifetime?				
Very concerned	8	12/148*	6	8/146*
Somewhat concerned	6	14/251	11	26/246
Not very concerned	11	11/102	13	13/99
Not at all concerned	21	14/67	37	26/71
Heard of topic of hereditary cancer risk?				
Not at all	11	11/98	14	14/99
A little	10	23/230	16	37/228
A lot	7	17/241	9	23/236
How likely you inherited cancer predisposition from parents?				
Very likely	5	3/64	8	5/63†
Somewhat likely	7	5/75	11	8/74
Somewhat unlikely	10	15/155	9	14/151
Very unlikely	9	20/213	18	38/215
Cancer in FDRs‡				
0	8	31/375*	13	46/369*
1	10	16/157	10	16/156
2	3	1/30	23	7/31
3-4	43	3/7	57	4/7

*$P < .01$ (χ^2 test).
†$P < .05$ (χ^2 test).
‡Score indicates number of categories of FDRs, including mother, father, sister, and brother, for which positive history of cancer was reported.

lations. No significant relationship was found between age and interest in being informed of a personal hereditary cancer risk (r [567] = −.01). However, age was significantly associated with interest in testing to determine risk (r [561] = .14; $P < .01$), with younger respondents expressing greater interest in testing.

Cancer concern. Relationships between interest in risk notification and testing and concern over developing cancer during one's lifetime were examined using χ^2 analyses (Table 3). Significant relationships were found between cancer concern and interest in risk notification (χ^2 [3] = 13.74; $P < .01$) and risk testing (χ^2 [3] = 43.64; $P < .00001$), with concern over developing cancer positively associated with interest in risk notification and testing.

Mental health. Relationships between mental health scores and interest in risk notification and testing were examined using point-biserial correlations. A significant relationship was found between mental health scores and interest in risk notification (r [567] = −.08; $P < .05$), with poorer mental health associated with less interest in risk notification. No relationship was found between mental health scores and interest in testing for hereditary cancer risk (r [561] = .00, not significant).

Awareness of topic of hereditary cancer risk. The relationship between awareness of the relationship between genes and cancer risk and interest in risk notification and testing was examined using χ^2 analyses (Table 3). Results indicated that awareness of hereditary cancer risk was not significantly associated with interest in risk notification. The relationship between awareness and interest in hereditary risk testing was marginal (χ^2 [2] = 5.05; $P = .08$), with awareness of hereditary cancer risk positively associated with interest in risk testing.

Perceived likelihood of personal hereditary cancer risk. The relationship between perceptions of the likelihood that one had inherited a gene that increased one's chances of developing cancer and interest in risk notification and testing was examined using χ^2 analyses (Table 3). No significant relationship was found between perceived likelihood of having a personal hereditary cancer risk and interest in risk notification (χ^2 [3] = 1.02). However, a significant relationship did emerge between perceived likelihood of having a personal hereditary cancer risk and interest in risk testing (χ^2 [3] = 7.79; $P < .05$), with a lower perceived likelihood of a personal hereditary cancer risk associated with less interest in risk testing.

History of cancer in FDRs. The relationships between extent of cancer in FDRs and interest in risk notification and testing were examined using χ^2 analyses (Ta-

ble 3). Because only one respondent indicated a history of cancer in all four categories of FDRs, this category was combined to create a single category of three or more FDRs with a cancer history. Results indicated a significant relationship between history of cancer in FDRs and both interest in risk notification (χ^2 [3] = 11.53; $P < .01$) and risk testing (χ^2 [3] = 15.74; $P < .002$). In both cases, a more extensive history of cancer in FDRs was associated with less interest in risk notification and testing.

General health perceptions. Relationships between health perception scores and interest in risk notification and testing were examined using point-biserial correlations. No significant relationships were found between health perception scores and interest in either risk notification (r [567] = .02) or testing (r [561] = .07).

Health care access. Relationships between various indices of health care access and interest in risk notification and testing were examined using χ^2 analyses (Table 2). No significant relationships were obtained between interest in risk notification and having private medical insurance coverage or a regular doctor. Similarly, no significant relationship was obtained between having a regular doctor and interest in risk testing. However, respondents without private medical insurance (ie, public or no insurance) were significantly less likely to express interest in hereditary risk testing (χ^2 [1] = 4.92; $P < .05$).

Protective health behaviors. The relationship between health behavior scores and interest in risk notification and testing was examined using χ^2 analyses. Results indicated a significant relationship between health behavior scores and interest in both risk notification (χ^2 [3] = 16.43; $P < .001$) and testing (χ^2 [3] = 9.36; $P < .05$) (Table 2). Engaging in fewer protective behaviors was associated with less interest in risk notification and testing.

Multivariate Predictors of Interest in Risk Notification and Testing

A pair of logistic regression analyses was conducted to examine multivariate predictors of interest in hereditary cancer risk notification and testing. Predictor variables included age (< 40 years, 40 to 59 years, > 60 years), sex, race (nonminority *v* minority), education (< high school degree *v* ≥ high school degree), concern about developing cancer and perceived likelihood of personal hereditary cancer risk (both dichotomized as very or somewhat *v* not very or not at all), mental health and health perception scores (both categorized as low, moderate, or high based on trichotomization of score distribution), insurance status (private insurance *v* public or no insurance), awareness of relationship between genes and cancer (categorized as not at all, a little, or a lot), extent of cancer in FDRs (dichotomized as zero to one *v* ≥ two categories of FDRs), and health behavior scores (zero to one *v* two to three health behaviors endorsed). Results of these analyses are listed in Table 4. The set of 12 predictor variables was significantly associated with interest in risk notification (model $\chi^2 = 37.55$, $df = 16$; $P < .002$). Sex (odds ratio = 2.16; $P < .05$), health behavior (odds ratio = .200; $P < .0001$), and health perception scores (odds ratio = 3.27; $P < .02$) were significant predictors of interest in risk notification, with female sex, the practice of fewer protective behaviors, and perceptions of good personal health associated with less interest in risk notification.

An identical logistic regression analysis was performed using interest in hereditary cancer risk testing as the dependent variable (Table 4). The set of 12 predictor variables was significantly associated with interest in risk testing (model $\chi^2 = 57.96$, $df = 16$; $P < .0001$). Sex (odds ratio = 2.77; $P < .005$), age (odds ratio = 2.64; $P < .05$), cancer concern (odds ratio = 2.76; $P < .002$), extent of cancer in FDRs (odds ratio = 4.44; $P < .005$), and health perception scores (odds ratio = 2.92; $P < .01$) were significant predictors of interest in risk testing. Female sex, increased age, less cancer concern, greater extent of cancer in FDRs, and perceptions of good personal health were associated with less interest in testing for hereditary cancer risk.

DISCUSSION

A great deal of interest was expressed in both notification and testing regarding personal hereditary cancer risk. Specifically, 87% of our sample indicated they would like to be notified if they possessed a hereditary predisposition to develop cancer. This is the exact proportion that responded affirmatively to an identical question in an earlier statewide survey.[17] Furthermore, 82% of our sample indicated a willingness to undergo a simple, inexpensive blood test to determine risk status. Our results thus confirm the high levels of interest in hereditary cancer risk notification and testing obtained in previous surveys.[14-16,18-22] However, while these previous studies focused on risk notification and testing with regard to specific cancer syndromes and/or assessed interest in samples of at-risk individuals, the present study indicates that the general public's interest in hereditary cancer risk testing and notification, in general, is also high.

Although interest in risk notification and testing was

Table 4. Logistic Regression Analysis of Interest in Hereditary Cancer Risk Notification and Testing

Variable	No Interest in Risk Notification		No Interest in Risk Testing	
	OR	95% CL	OR	95% CL
Race‡	1.40	0.36-5.38	0.68	0.14-3.25
Education§	0.70	0.28-1.77	1.31	0.53-3.22
Age, years				
40-59 v ≤ 39	1.19	0.84-1.69	1.06	0.53-2.12
≥ 60 v ≤ 39	0.94	0.31-2.85	2.64*	1.15-6.06
Sex‖	2.16*	1.09-4.55	2.77†	1.45-5.31
Cancer concern¶	1.86	0.90-3.88	2.76†	1.48-5.10
Medical insurance**	0.98	0.43-2.25	0.73	0.36-1.48
Mental health scores				
Moderate v low	0.80	0.34-1.88	0.68	0.32-1.45
High v low	0.56	0.20-1.56	1.19	0.54-2.62
Health behavior††	0.20†	0.10-0.39	0.54	0.27-1.09
Aware of topic of hereditary cancer risk				
A little v not at all	0.96	0.40-2.30	1.12	0.51-2.47
A lot v not at all	0.57	0.21-1.56	0.51	0.21-1.23
Likelihood of hereditary risk‡‡	1.38	0.52-3.64	1.47	0.63-3.43
Cancer in FDRs§§	1.77	0.43-7.26	4.44†	1.62-12.18
Health perception scores				
Moderate v low	1.70	0.55-5.27	1.48	0.59-3.67
High v low	3.27*	1.21-8.79	2.92†	1.31-6.50
Model χ^2	37.55†		57.96†	

Abbreviations: OR, odds ratio; 95% CL, 95% confidence limit.
*$P < .05$.
†$P < .01$.
‡Minority v white.
§High school degree or more v some high school or less.
‖Female v male.
¶A little or not at all concerned v very or somewhat concerned.
#Excellent or good v average or poor.
**Private health insurance v public/no health insurance.
††0 to 1 health behaviors v 2 to 3 health behaviors reported.
‡‡Very or somewhat likely v somewhat or very unlikely.
§§2 to 4 categories of FDRs with cancer v 0 to 1 category of FDRs.

high, it was not universal. Female sex, performance of fewer health behaviors, and better perceived health were significant multivariate predictors of disinterest in risk notification. Female sex, better perceived health, older age, greater concern about developing cancer, and a greater history of cancer in FDRs were significant multivariate predictors of disinterest in risk testing. Our results confirm previous research, which found greater cancer concern,[14,20] younger age,[20] and performance of fewer health behaviors[17] to be associated with greater interest in risk notification and/or testing. The link between better health perceptions and disinterest in these services was also anticipated based on difficulties often faced in getting healthy, asymptomatic individuals to consider future health risks and adopt health-sustaining behaviors.[25,26] It should be noted that many of the variables we examined were not significantly associated with interest in risk testing and notification. Although our sample size provided adequate statistical power to detect even small true effects, our negative results cannot be interpreted as evidence that variables such as education or race are not related to interest in risk notification and testing, only that they were not related to interest in the particular population sampled in this study.

Previous research has found that women from BRCA1 families evidence greater interest in risk testing and notification, specifically for BRCA1.[11,22,23] In contrast, women in the present study were two to three times more likely than men to state disinterest in risk notification and testing. Several explanations for this difference are possible. First, results may have differed because we asked about generic interest in cancer risk testing and notification, while prior studies have asked about interest among women with regard to breast and ovarian cancer syn-

drome—a syndrome primarily affecting women. Second, greater disinterest among women may reflect greater knowledge of the potential risks associated with risk testing as a result of the widespread media attention devoted to hereditary breast and ovarian cancer syndromes. This is likely to change, of course, as the number of identified hereditary syndromes affecting males or both sexes equally increases.

A more extensive history of cancer in FDRs was the best multivariate predictor of disinterest in risk testing (Table 4). In particular, 29% of respondents with cancer in two or more categories of FDRs would not be interested in undergoing a blood test to determine carrier status compared with 12% of respondents with cancer in one or fewer categories of FDRs. This finding raises the sobering possibility that individuals who might benefit most from risk testing, ie, those at greatest risk for positive carrier status, are least likely to be interested in these services. However, one explanation of this finding is that individuals with a more extensive history of cancer may be more knowledgeable regarding both the potential risks of testing and the present lack of demonstrably effective means for a positive carrier to reduce his or her personal cancer-related mortality and morbidity. Thus, disinterest in testing among those with a more extensive family history of cancer might well reflect a rational assessment of current costs and benefits associated with testing. On the other hand, disinterest might stem from a more irrational process involving fear-motivated avoidance of testing simply because of perceptions of high personal risk for positive carrier status. To the degree that this latter process underlies disinterest in testing, recruitment of individuals at high risk for positive carrier status into risk testing and notification programs will pose a considerable challenge. The utility of hereditary risk testing as a cancer control strategy might then hinge on outreach efforts to identify and recruit high-risk individuals into testing and notification programs. As is true of any cancer control program, rational appeals will need to be combined with attention to psychologic impediments to participation, such as cancer-related fears and anxiety. Of course, such outreach efforts are only justified if the risks of hereditary risk testing are reasonable in light of the benefits associated with testing.

Finally, contrary to expectation, increased awareness of the potential relationship between genes and cancer risk was not associated with interest in either risk testing or notification. However, as suggested previously, greater awareness may be associated with better knowledge of the poor ratio of risk to benefit currently associated with hereditary risk testing. However, the proportion of individuals who were relatively unaware of the entire topic of hereditary cancer syndromes at the time of this survey (September 1995) was very notable. Specifically, 18% of respondents stated that they had not heard of this topic at all, while an additional 40% indicated that they had heard only a little. Thus, many individuals with little knowledge of hereditary risk testing and notification nevertheless expressed interest in these services. This underscores the paramount importance of pretesting education and counseling recommended by current guidelines.[30] Provision of education and counseling is relatively easy in the context of the tightly controlled testing protocols available today on a limited basis. However, provision of suitable education and counseling will constitute a significant challenge should consumer demand for testing and notification services result in expansion of the range of clinical settings offering these services.

Current guidelines for hereditary risk testing recommend that testing be limited to testing for well-defined hereditary cancer syndromes in groups of at-risk individuals.[30] Thus, one might question the relevance of our data given both its assessment of the general population and its lack of focus on a specific hereditary syndrome. Indeed, the risk-benefit ratio associated with testing for a specific cancer hereditary cancer syndrome would be expected to be a strong determinant of interest in risk testing and notification. Our assessment of generic interest in these services thus obscures potential real differences in interest associated with specific cancers. However, we believe that our data help to gauge potential demand for risk testing in anticipation of what we believe to be two likely trends: expansion of the range of hereditary syndromes for which testing will be possible and increased demand for expansion of the clinical settings in which testing will be available. The latter will stem from two interconnected sources: interested consumers, many at low risk for positive carrier status, who are essentially seeking reassurance of their low-risk status; and providers seeking to develop risk testing and notification programs as marketable clinical services, partially in response to expressed consumer interest.

Questions can also be raised regarding the utility of assessing hypothetical interest in risk testing and notification rather than actual interest. For example, our question regarding interest in risk testing described the testing process as both simple and inexpensive. Although this does not accurately describe the current status of risk testing, we sought to identify the public's basic interest in risk testing given absence of constraints of

convenience and cost. Additionally, prior experience with risk testing for Huntington's disease found that while expressed interest in genetic testing was high, few potential gene carriers participated in genetic testing.[31] Data from several ongoing hereditary risk testing and notification programs suggest a similar effect, with actual uptake of services in only approximately 40% of eligible high-risk individuals.[11,23,32] In contrast, however, one study found that 80% of 36 members of two families in which the BRCA1 mutation had been identified accepted an offer of genetic risk testing.[32] This latter rate of actual acceptance of risk testing is comparable to that found in surveys of hypothetical acceptance of risk notification and testing, such as ours. Actual acceptance of risk notification and testing services are likely to vary as a function of cost and convenience, the nature and immediacy of the threat of being a gene carrier, and the clarity and perceived efficacy of risk-reducing options for gene carriers.[32] Thus, in some instances, the hypothetical demand for risk notification and testing services reported in recent surveys might be a good estimate of actual demand for these services.

In conclusion, current recommendations suggest that testing for hereditary risk be limited to well-defined cancer-susceptibility syndromes in individuals with either a strong family history of cancer or early onset of malignant disease in the context of clinical research protocols.[30] The purpose of testing then is to remove ambiguity regarding gene carrier status in the hope that this will allay anxiety in noncarriers and lead to appropriate cancer-control behaviors in gene carriers. Given this context, our findings pose a significant challenge: How can the disinterest in risk testing and notification evidenced by women and individuals with stronger family histories of malignancy be overcome? Furthermore, expansion of the number of identified cancer susceptibility syndromes, coupled with greater clinical availability of testing, is likely to lead to significant public demand for risk testing. Because many of these individuals will not possess a strong family history of cancer, the basic function of risk testing will then be to provide reassurance regarding low hereditary risk status. Given this context, providers of risk testing and notification services will confront a different challenge: how to ensure that individuals understand that negative gene carrier status does not necessarily imply the absence or even decreased risk for malignant disease.

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