Building Systems of Breast Cancer Care:
A Comprehensive Review of Literature and Web Resources

A publication of the Healthcare Association of New York State (HANYS)

HANYS represents more than 500 non-profit and public hospitals, nursing homes, home care agencies, and other health care organizations throughout New York State.
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Introduction

Building Models of Breast Cancer Care: A Review of Literature and Web Resources© is a product of the Healthcare Association of New York State’s Breast Cancer Demonstration Project. This tool was created to provide health care facilities with a comprehensive, organized review of literature on breast cancer services. Most staff persons working in health care facilities do not have the time or resources to participate in such an extensive review. In preparing this document, months of directed activity were spent researching more than 300 articles and 200 Internet sites. The Healthcare Association of New York State (HANYS) hopes that health care facilities will find this document useful in supporting their efforts to enhance breast cancer care services.

This literature review is intended as a reference tool for facilities working to provide and improve breast cancer services. It is a guide and springboard for health care facilities to use in designing a model of integrated, coordinated, and comprehensive breast health services in a network setting.

HANYS’ Breast Cancer Demonstration Project is a two-year program funded by the New York State Assembly that began in 1998. HANYS is partnering with seven sites around the state to develop, implement, and evaluate a model for integrated breast health services. These sites represent 10 health care systems.

Increasingly, hospitals and other health care providers are affiliating into networks and health care systems. The project’s goal is to develop a model of integrated, coordinated, and comprehensive breast health services in a network setting.

Literature searches for this review were conducted primarily in MedLine and HealthSTAR from July 1998 through February 1999. The majority of the articles were published in 1997 – 1998 with more than 90% published since 1993. Recent publications from major medical, quality, and management journals are included.

Additionally, an extensive search of breast cancer information was performed on the Internet. Of the 200 latest sites reviewed, HANYS identified 39 sites for annotation and inclusion in the main body of this Literature Review. Criteria for inclusion include comprehensiveness of information, reliability and quality, ease of navigation, and mechanisms for feedback and interactivity. Appendix A contains HANYS’ complete archive of breast cancer Web sites.
The Comprehensive Review’s organizational structure is built on an array of issues relevant to areas of breast cancer services. The document is divided into three main profiles: Integrated Health Care Systems, Patient Characteristics, and Building a Model of Breast Cancer Treatment.

The Integrated Health Care Systems profile has categories ranging from integrated systems and cancer care models to quality improvement and measurement tools. The Patient Characteristics Profile reviews outreach, education, and treatment information that is specific to certain patient populations. The profile categories in Building A Model for Breast Cancer Treatment range from prevention and treatment to quality of life and socioeconomic factors. Narration preceding each of the categories is derived from the material. Please note that many of the articles are followed by Web addresses that will take the reader directly to the document or Web page indicated in the annotation.

HOW TO USE THIS DOCUMENT

While these article reviews provide an overview of relevant issues, readers are encouraged to consult the original articles for details of reported studies and programs. The annotations and remarks are intended to direct readers to the appropriate resources rather than substitute for them.

The categories in the document are not mutually exclusive. Many times a particular article may contain information relevant to more than one category or profile. Each article is reported only once. Please keep this in mind when using the document to assist in your research.

We hope that this document will be useful to health care facilities and that it will become a valued resource. HANYS invites and encourages questions and comments on this literature review. Please direct comments to:

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Appendix A: Breast Cancer Web Sites
Integrated Health Care Systems

DESIGNING AND BUILDING AN INTEGRATED SYSTEM

Health systems across the country are developing integrated health care centers designed to serve the health needs of women. Restructuring trends in the health care industry include collaboration, service integration, management consolidation, and work force redesign. Service integration across organizations is an important strategy for improving patient care services, customer satisfaction, cost-effectiveness, and efficiency. The integration of clinical medicine, systems thinking, and quality management disciplines provides needed tools and skills and identifies key areas and learning opportunities to improve the quality of service delivery.

BUILDING KNOWLEDGE OF HEALTH CARE AS A SYSTEM. This article presents a 10-step exercise for building knowledge of an interdependent system of health care. This exercise can be used for designing and relating new improvement efforts to the general work of the organization. Batalden, P. B. & Mohr, J. J. (1997). Quality Management in Health Care, 5 (3), 1 – 12.


MANAGING AND REDESIGNING THE CONTINUUM OF CARE: THE VALUE CHAIN MODEL. This article describes the value chain model designed to assist managers, physicians, and organizations in managing and redesigning the continuum of care. This model helps to identify key areas and learning opportunities to improve the quality of services delivered. Fleschut, K., Caldwell, C. & Beyt, Jr., B. E. (1996). Quality Management in Health Care, 5 (1), 42 – 48.

INTEGRATING WOMEN’S HEALTH CARE – SERVING THE WHOLE WOMAN. In this article, six keys to successfully launching a comprehensive care program are presented; all are insights that systems have gained in developing their own programs. Meade, V. (1997, October). The Quality Letter for Healthcare Leaders, 9 (9), 2 – 10.
DESIGNING NEW SERVICES IN HEALTH CARE ORGANIZATIONS: A STEP-BY-STEP METHODOLOGY. The author describes a service design model to ensure that a health care organization can develop integrated services that meet process and performance requirements, as well as national standards. The model focuses on client satisfaction and creates an environment ripe for contract renewal. Remus, B. (1998, July). QRC Advisor, 14 (9), 1 – 6.

HEALTH PLAN COLLABORATION

Whether managed care has delivered its promise to create more fully integrated quality cancer care is still subject to debate. Collaborations between health plans and clinical care providers occur in a number of ways. Strategies for collaborations include: developing a shared purpose; creating an open, safe environment; including all who share a common purpose and encouraging diverse viewpoints; negotiating agreement; and insisting on fairness and equity in the application of rules.

COLLABORATING WITH MANAGED CARE ORGANIZATIONS FOR MAMMOGRAPHY SCREENING AND RESCREENING. This article describes challenges and opportunities presented by managed care for the major components of clinical prevention service programs such as breast cancer prevention and control. The final section presents some of the factors that make collaboration difficult and factors that can enhance future collaborations. Center for Disease Control and Prevention. (1997). Available from the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Mailstop K-64, 4770 Buford Highway, NE, Atlanta, GA 30341-3724. [On-line] Available: http://www.cdc.gov/nccdphp/dcpc/publica.htm#breast


MANAGED CARE AND ITS FUTURE IN BREAST CENTER MANAGEMENT. The authors examine the impact of managed care on breast health care service delivery including the issues of downsizing, reorganized administration, flexible staffing during light and/or peak patient-load hours, the addition of mobile mammography, and increased malpractice and malpractice litigation. Jamieson, P. A. & Matthews, R. (1997). Oncology Issues, 12 (6), 20 – 21.

WHAT IS PROPER CANCER CARE IN THE ERA OF MANAGED CARE? This article presents views on disease management plans for cancer. Opportunities for the oncology community to define and promote the integration of cancer care in collaboration with managed care organizations are described. Monaco, G. P. & Goldschmidt, P. (1997). Oncology, 11 (1), 65 — 71; discussion 72, 78.

CANCER CARE MODELS

Many hospitals and health systems are developing integrated models of breast cancer treatment to improve the care they provide to patients. Establishing clinics in which information, screening, and diagnosis of breast cancer are readily available helps decrease women's anxiety and enhance their ability to self-advocate within the health care system. These articles describe how models are developed, implemented, evaluated, and sustained.

COR HEALTHCARE RESOURCES. This article describes the design and implementation of a center to provide comprehensive integrated cancer prevention, detection, and treatment. Results include reorganization of medical staff and administrative reporting and management responsibilities; adoption of critical pathways and outcomes measures/monitoring across all product lines; development of community cancer education plan; and development of a supportive care program. (1998, May). Strategies for Healthcare Excellence, 11 (5), 1 – 12.

BENEFITS OF A MULTIDISCIPLINARY APPROACH TO BREAST CARE. The University of Michigan Breast Care Center (BCC) was established in 1985 to provide comprehensive, multidisciplinary diagnosis and treatment of benign and malignant breast disease. This work presents an overview of the experience in the BCC and assesses the clinical, academic, financial, and educational effectiveness of the program. The authors suggest that a multidisciplinary approach to patient care can be clinically, financially, and academically productive. August, D. A., Carpenter, L. C., Harness, J. K., Delosh, T., Cody, R. L., Adler, D. D., Oberman, H., Wilkins, E., Schottenfeld, D., McNeely, S. G., et al. (1993). Journal of Surgical Oncology, 53 (3), 161 – 167.

MODEL OF COMPREHENSIVE DIAGNOSIS AND CARE FOR BREAST CANCER PATIENTS. This article discusses the establishment of a comprehensive program for the evaluation and care of women with breast cancer and the benefits that may be realized from such an approach. The goals of this system are the facilitation of optimal medical care; patient convenience; clinical efficiency; patient access to supportive services from social workers, other allied health professionals and peer counselors; and clinical and outcomes research. August, D. A., DiPaola, R. S., Kearney, T. & Hait, W. (1996). New Jersey Medicine, 93 (5), 27 – 34.

ADVANCING WOMEN’S HEALTH: HEALTH PLANS’ INNOVATIVE PROGRAMS IN BREAST CANCER. This publication summarizes findings from the American Association of Health Plan’s assessment of four health plans that have implemented model programs to address the medical and psychosocial needs of women with breast cancer. The plans are Humana Health Care, Keystone-Mercy Health, Blue Cross Blue Shield of Massachusetts, and Kaiser Permanente. Included are descriptions of patient, system, and
community-level strategies of enhancing the prognosis for patients with breast cancer and
the effectiveness of the providers who care for them. Bloom, F. B., Rolnick, S. J.,

ESTABLISHING A COLLABORATIVE PRACTICE IN A COMPREHENSIVE BREAST
CLINIC. A comprehensive breast clinic was developed, incorporating nurse practitioners
and physicians in a collaborative model of care. Defining roles within the model was an
ongoing process as each provider developed areas of expertise and interest. Dontje, K. J.,

IMPROVING THE DELIVERY OF CLINICAL PREVENTIVE SERVICES TO WOMEN
IN MANAGED CARE ORGANIZATIONS: A CASE STUDY ANALYSIS. This study
examines the key features of breast cancer prevention programs in six managed care plans
and one group medical practice. The authors state that successful programs require substan-
tial resources and planning; are population based; gain the support of providers and patients
early; have clear, established systems for collecting and using data; and have a monitoring
Mathematica Policy Research, Inc.

AMERICA’S 10 BEST BREAST CANCER CENTERS. This article identifies some of the lead-
ing breast care centers in the United States. According to the author’s criteria, variations in
the quality of care at the best breast cancer centers and many of the others is far greater than
that for maternity centers and women’s health centers. Profiles of breast cancer centers that
are highly regarded by the author are provided. Korn, P. (1997). Self Magazine, 10,
211 – 214.

UNDERSTANDING MEDICAL SYSTEMS. The physician who is interested in learning about
the nature of systems, how to control them, and how to improve them can significantly
influence medical systems. An understanding of the structures and dynamics of systems
combined with clinical knowledge can assist physicians in the process of diagnosing system
faults and designing remedies. This paper explores the nature of medical systems and devel-
ops ideas, their possible application to medicine, and the activities of physicians. Nolan, T.

ONCOLOGY MANAGEMENT BY THE “NEW” VETERANS HEALTH ADMINISTRATION.
The Veterans Health Administration (VHA) of the Department of Veterans Affairs
manages the largest integrated health care system in the United States. VHA’s transforma-
tion into a system of integrated networks supports and promotes their cancer expertise. The
VHA initiatives as described in this article are synergistically working to enhance the con-
sistency and comprehensiveness of high-quality, patient-centered oncology services.
INTERDISCIPLINARY PROGRAM
GUIDELINES

These articles discuss examples of clinical pathways and interdisciplinary programs being used for the management of breast disease. The articles review both how these programs were developed and the effect each program has had for patients and their families.

STANDARDS FOR CANCER PROGRAMS. The Association of Community Cancer Centers’ Standards for Cancer Programs has been established to assist cancer programs that want to develop and/or maintain a comprehensive interdisciplinary program that meets the needs of cancer patients and their families. These standards were developed to reflect important components for a cancer program. They are not intended to act as an accrediting or credentialing mechanism. Association for Community Cancer Centers. (1997, January). [Online] Available: http://www.assoc-cancer-ctrs.org/


THE REVLON/UCLA BREAST CENTER PRACTICE GUIDELINES FOR THE TREATMENT OF BREAST DISEASE. This document includes recommendations regarding treatments associated with favorable patient outcomes. The authors suggest that in areas where uncertainty regarding treatment strategies exists, a discussion with the patient of the pros and cons of various treatments should take place. Love, S. M., McGuigan, K. A. & Chap, L. (1996). The Cancer Journal from Scientific American, 2 (1), 2 – 15.

CONTINUITY OF INFORMATION FOR BREAST CANCER PATIENTS: THE DEVELOPMENT, USE AND EVALUATION OF A MULTIDISCIPLINARY CARE-PROTOCOL. This paper presents a protocol that integrates medical, nursing, and a variety of extramural events and activities into a comprehensive description of 15 moments in the care of breast cancer surgery patients. Among innovations, the protocol includes information about psychosocial guidance following diagnosis, the discharge procedure, and contact with fellow patients. van-Wersch, A., Bonnema, J., Prinsen, B., Pruyn, J., Wiggers, T. & van-Geel, A. N. (1997). Patient Education and Counseling, 30 (2), 175 – 186.
BREAST CANCER SYSTEM CHARACTERISTICS

Geographic Issues

This section describes the implication of geographic location for a breast cancer center as a predictor of quality of care. The articles survey whether treatments and outcome statistics vary from rural to urban hospitals. Comparisons were also drawn for rural patients who travel to urban centers to receive cancer care.

URBAN-RURAL DIFFERENCES IN THE MANAGEMENT OF BREAST CANCER. This paper compares the pattern of care among three breast cancer populations: rural patients diagnosed in rural hospitals; rural patients traveling to urban medical centers; and urban patients diagnosed in urban medical centers. Compared with urban patients, rural patients diagnosed in rural hospitals were less likely to have staged tumors and more likely to have node dissections. Rural patients traveling to urban centers were less likely to have limited surgery, hormone therapy, or a biopsy as a first-step surgical procedure, and more likely to have node dissection. Howe, H. L., Katterhagen, J. G., Yates, J. & Lehnherr, M. (1992). Cancer Causes and Control, 3 (6), 533 – 539.

GEOGRAPHIC VARIATION IN THE USE OF BREAST-CONSERVING TREATMENT FOR BREAST CANCER. This article examines the extent to which breast-conserving treatment has been adopted in various regions of the country and whether characteristics of hospitals and patients predict its use. It concluded that there is substantial geographic variation in the use of breast-conserving surgery, which cannot be explained by differences in hospital characteristics. Nattinger, A. B., Gottlieb, M. S., Veum, J., Yahneke, D. & Goodwin, J. S. (1992). New England Journal of Medicine, 326 (17), 1102 – 1107.

Hospital Size/Type

The articles in this section compare patient treatment at teaching hospitals, community hospitals, large medical centers, and smaller centers. These articles consider how the size and type of hospitals may affect physician education, treatment, and diagnosis. The authors also compare centralized care to decentralized care and assess the impact of hospital volume on patient outcomes.

DELAY IN DIAGNOSIS AND TREATMENT OF BREAST CANCER: IMPLICATIONS FOR EDUCATION. This study evaluates 225 women from a public hospital, a university hospital cancer center, and a private practice. Time spans between evaluation, diagnosis, and initiation of treatment were examined. The elapsed times for the diagnosis, treatment, and combined intervals were all significantly longer for women seen in the public hospital when compared with private practice. Bedell, M. B., Wood, M. E., Lezotte, D. C., Sedlacek, S. M. & Orleans, M. M. (1995). Journal of Cancer Education, 10 (4), 223 – 228.


TREATMENT DIFFERENCES AND OTHER PROGNOSTIC FACTORS RELATED TO BREAST CANCER SURVIVAL, DELIVERY SYSTEMS AND MEDICAL OUTCOMES. The objective of this study was to determine differences in and relative importance of treatment methods by hospital type and their effect on survival of breast cancer patients. The analysis was conducted within a population of breast cancer patients diagnosed from 1984 through 1990, stratified by hospital type and treatment method. Lee-Feldstein, A., Anton-Culver, H. & Feldstein, P. J. (1994). *Journal of the American Medical Association, 271* (15), 1163 – 1168.

HOSPITAL VOLUME DIFFERENCES AND FIVE-YEAR SURVIVAL FROM BREAST CANCER. The purpose of this study was to determine the effect of hospital volume on long-term survival for women with breast cancer. The authors found that at five years, patients from very low-volume hospitals had a 60% greater risk of all-cause mortality than patients from high-volume hospitals did. Roohan, P. J., Bickell, N. A., Baptiste, M. S., Therriault, G. D., Ferrara, E. P. & Siu, A. L. (1998). *American Journal of Public Health, 88* (3), 454 – 457.

HOSPITALS AND ANTITRUST: DEFINING MARKETS, SETTING STANDARDS. This paper argues for a different approach to market definition in areas where insurance plans that contract selectively are a significant market presence. Such a proposed approach is described and some policy implications are drawn. Zwanzgler, J., Melnick, G. & Eyre, K. M. (1994). *Journal of Health Politics, Policy and Law, 19* (2) 423 – 447.
Staffing

Integrated programs can require changes and assimilation of staffing roles. As skills are shared and processes are streamlined, communications among staff may also change. The following articles examine the roles of nursing leaders and patient navigators, both of whom work closely with patients and staff to review and clarify treatment processes.


THE ROLE OF THE COMPREHENSIVE BREAST CENTER. This article describes the role of the nurse practitioner in relation to a comprehensive breast center, as well as how the nurse practitioner can improve the provision of primary breast care. It identifies quality in potential consultants and effective collaboration and communication strategies with other members of the health care team, including the patient and family. Coleman, C. (1993). Nurse Practitioner Forum, 4 (2), 110 – 114.

EXPANDING ACCESS TO CANCER SCREENING AND CLINICAL FOLLOW-UP AMONG THE MEDICALLY UNDERSERVED. Research shows that blacks have the highest cancer incidences and mortality rates in the United States. Higher mortality rates have been attributed to higher incidence in some sites and to later-stage diagnoses in others. To address these problems, expanded cancer screening in an inner city public hospital and a patient navigator intervention were proposed. Patient navigators acted as advocates for patients with abnormal screening results. Of patients navigated, 87.5% completed recommended breast biopsies, compared with 56.6% of the non-navigated patients. Among those with a biopsy, navigated patients had their procedures sooner than those not navigated. Freeman, H. P., Muth, B. J. & Kerner, J. F. (1995). Cancer Practice, 3 (1), 19 – 30.

Payers

This section examines patient outcomes related to insurance status. Differences in private insurance and public programs such as Medicaid are reviewed. Preventative services and fee-for-service programs are also discussed.


TYPE OF HEALTH CARE COVERAGE AND THE LIKELIHOOD OF BEING SCREENED FOR CANCER. This study found that adults who had private outpatient insurance were more likely to undergo recommended cancer detection procedures than those who did not. Adults who belonged to an HMO were more likely to receive Pap
smears, mammograms, and fecal blood tests than those covered by indemnity plans. The authors stated that receiving care primarily from one doctor significantly increased the likelihood of having screening procedures, irrespective of the type of health care plan. Gordon, N. P., Rundall, T. G. & Parker, L. (1998). Medical Care, 36 (5), 636 – 645.

BREAST CANCER SURVIVAL AND TREATMENT IN HEALTH MAINTENANCE ORGANIZATION AND FEE-FOR-SERVICE SETTINGS. This study examined whether there is a difference in the treatment and outcome for female patients with breast cancer enrolled in HMOs versus a fee-for-service setting by comparing the ten-year survival and initial treatment of patients with breast cancer enrolled in both types of plans. The authors found that the long-term survival outcomes in the two HMOs in this study were at least equal to outcomes in the fee-for-service system. In addition, the use of recommended therapy for early stage breast cancer was more frequent in the two HMOs. Potosky, A. L., Merrill, R. M., Riley, G. F., Taplin, S. H., Barlow, W., Fireman, B. H. & Ballard-Barbash R. J. (1997). Journal of the National Cancer Institute, 89 (22), 1683 – 1691.

MEDICAL OUTCOMES OF CARE FOR BREAST CANCER AMONG HEALTH MAINTENANCE ORGANIZATION AND FEE-FOR-SERVICE PATIENTS. This study concluded that, despite differences in the type of health insurance coverage, there do not appear to be systematic differences in medical outcomes for breast cancer among women who are treated by the same medical care provider. Vernon, S. W., Heckel, V. & Jackson, G. L. (1995). Clinical Cancer Research, 1 (2), 179 – 184.

QUALITY IMPROVEMENT AND MEASUREMENT

Overview

Health care quality has become a popular and well-scrutinized media topic. Authors have examined how services are used inappropriately, not used efficiently, or not used at all. Articles have assessed both the causes of quality problems and ways to approach quality in medical care.

CONTINUOUS IMPROVEMENT AS AN IDEAL IN HEALTH CARE. This article describes quality improvement in contrast to the “Theory of Bad Apples.” According to that theory, quality improvement is a matter of finding the one person, process, or product that causes a problem and getting rid of the instigator. In the author’s view, quality improvement involves a number of small steps: leaders taking leadership roles in improving quality, substantial investment in the process of improvement, reestablishing respect for the health care worker, maintaining communications with customers and suppliers, using appropriate improvement tools, and “organizing for quality.” Berwick, D. M. (1989). New England Journal of Medicine, 320 (1), 53 – 56.

THE URGENT NEED TO IMPROVE HEALTH CARE QUALITY. This article examines alleged widespread quality problems in American medicine. The authors state that these problems, which may be classified as under-use, overuse, or misuse, occur in small and large communities alike, in all parts of the country, and with approximate equal frequency in managed care and fee-for-service systems of care. The authors suggest that managed care

REDUCING TREATMENT VARIATION IS KEY TO MANAGING CANCER. Cancer and disease management specialists have found a high level of variability in treatment strategies for cancer. This variability, the authors assert, often leads to unnecessary duplication of services and high rates of hospitalization. Disease management studies used by the authors showed most of the costs of cancer care were related to hospital admissions. The authors also found that reductions in treatment variation in the management of cancer decreased the cost of hospital admissions by 25%. (1998, August). Healthcare Demand & Disease Management, 4 (8), 113 – 115.

Engaging Clinicians

*Physicians sometimes express skepticism towards quality improvement (QI) and obtaining their support for QI projects can be challenging. These articles present ways to encourage physician involvement in quality measurement and clinical improvement processes.*

IF IMPROVEMENT OF THE QUALITY AND VALUE OF HEALTH AND HEALTH CARE IS THE GOAL, WHY FOCUS ON HEALTH PROFESSIONAL DEVELOPMENT?
The author discusses organization-centered and issue-centered strategies for the continual improvement of quality and value of health care. The paper explores these strategies and in their context, considers the application of health professional development strategies for the improvement of health care. Batalden, P. B. (1998). Quality Management in Health Care, 6 (2), 52 – 61.

ENGAGING CLINICIANS IN A QUALITY IMPROVEMENT STRATEGY FOR EARLY-STAGE BREAST CANCER TREATMENT.

COOPERATION: THE FOUNDATION OF IMPROVEMENT.

PHYSICIANS AS LEADERS IN THE IMPROVEMENT OF HEALTH CARE SYSTEMS.
This paper is intended to be a primer for physicians who are asked to lead a quality improvement initiative. The author describes a body of knowledge that physician leaders may utilize in leadership. Case examples are used to address such topics as the nature of leadership, the relation between leadership and management, and ways in which physicians might approach a new leadership assignment. Reinertsen, J. L. (1998). Annals of Internal Medicine, 128 (10), 833 – 838.
QI Program Application

When planning for quality improvement, staff persons may consider the number and types of participants, the topic areas for their inquiry, the tools they will use, and the methods for evaluating progress. The authors of the articles in this section suggest that the above processes are key components to quality improvement in all facets of chronic disease management. The authors describe certain consistent approaches to quality improvement: cooperation, creativity, and flexibility.

A MODEL FOR COLLABORATION IN QUALITY IMPROVEMENT PROJECTS: IMPLEMENTING A WEIGHT-BASED HEPARIN DOSING NOMOGRAM ACROSS AN INTEGRATED HEALTH CARE DELIVERY SYSTEM. This article describes a system-level clinical quality improvement department within an integrated delivery system that was established to facilitate collaboration on clinical quality improvement initiatives. A model was developed that used expertise within the system, avoided duplication of efforts, and maintained buy-in for the project’s interventions at the point of service delivery. The authors discuss ways that this model has been successfully applied to other quality improvement projects. Berry, B. B., Geary, D. L. & Jaff, M. R. (1998). Joint Commission Journal of Quality Improvement, 24 (9), 459 – 469.

KEYS FOR SUCCESSFUL IMPLEMENTATION OF TOTAL QUALITY MANAGEMENT IN HOSPITALS. This article reports the findings of an analysis of continuous quality improvement (CQI) or total quality management (TQM) programs in 10 hospitals. This analysis is the result of a two-year study designed to identify and assess the ingredients leading to the successful implementation of CQI programs in acute care hospitals. Carman, J. M., Shortell, S. M., Foster, R. W., Hughes, E. F. X., Boerstler, H., O’Brien, J. L. & O’Connor, E. J. (1996). Health Care Management Review, 21 (1), 48 – 60.


CONTINUOUS QUALITY IMPROVEMENT AND PRIMARY CARE. This paper provides a broad overview of CQI and its applications in primary care settings. It encourages clinicians and quality improvement personnel to reach consensus on the variations to be reduced or eliminated and those to be celebrated for being responsive to patients’ preferences. Clancy, C. M. (1998). Medical Care, 36 (5), 619 – 620.

MEDICAL TECHNOLOGY ASSESSMENT: A MODEL FOR INFORMED DECISION MAKING. This manual is a reference guide for facilities and administrators who are determining whether to expand medical technology at their sites. The manual includes both an assessment model and case studies, and focuses on seven types of assessment: medical, community, facility, vendor/equipment, financial, integration of assessments, and re-assessment. Hospital Association of New York State. (1991). Albany, New York: Author.
BUILDING BETTER TEAM CHARTERS: AN EXAMPLE FROM REENGINEERING THE PREOPERATIVE SYSTEM. This article explores the use of charters to guide quality improvement efforts. Charters may be used to address small processes in a way that use time and resources efficiently. The authors explain the effectiveness of a quality improvement project to illustrate a systematic approach to the development of charters. Lam, H. C., Cretin, S. & Norman, D. (1998). Quality Management in Health Care, 6 (2), 62 – 73.

TOTAL QUALITY MANAGEMENT IN HOSPITALS. The authors surveyed quality coordinators and quality improvement team leaders to collect both site-level and team-level data on quality improvement in Veterans Health Administration hospitals. They found that the age of the quality council, overall facility commitment to total quality management philosophy, and physician commitment are significant in explaining numbers of teams, training intensity, and total perceived improvement at this sample of medical centers. Lammers, J. C., Cretin, S., Gilman, S. & Calingo, E. (1996). Medical Care, 34 (5), 463 – 478.

CONTINUOUS QUALITY IMPROVEMENT IN PRIMARY CARE: WHAT’S HAPPENING? The purpose of this study was to measure the attitudes, activities, and organizational cultures concerning CQI in a group of primary care clinics. Many of the clinics had previous CQI team experiences and expressed favorable attitudes for CQI concepts. However, the authors found that the clinics that were surveyed demonstrated a limited depth of understanding or action and needed help building skills and experiences for the required care improvements. Solberg, L. I., Brekke, M. L., Kottke, T. E. & Steele, R. P. (1998). Medical Care, 36 (5), 625 – 635.

BEYOND CLINICAL PATHS: ADVANCED TOOLS FOR OUTCOMES MANAGEMENT. This monograph provides a detailed overview of quality improvement by focusing on examples drawn from the experiences of various hospitals. The editor ties these examples to two types of initiatives: clinical process improvement initiatives and information technology solutions. Spath, P. (Ed.). (1997). Chicago: American Hospital Publishing, Inc.

A BREAST CANCER CARE REPORT CARD. AN ASSESSMENT OF PERFORMANCE AND A PURSUIT OF VALUE. The report card, a publicly released, standardized report on quality, has received widespread interest as a method to evaluate physician performance. The authors argue that current report cards do not provide sufficient information to allow purchasers of health care to accurately assess the professional performance of breast care providers. They propose an expanded report card on breast cancer care. West, J. G., Sutherland, M. L., Link, J.S. & Margileth, D. A. (1997). Western Journal of Medicine, 166 (4), 248 – 252.
MEASUREMENT TOOLS

Overview

The process of integrating and improving breast cancer services can require a number of stages of planning and evaluation. Various types of clinical procedures have been studied and improved using similar models of testing, data collection, and evaluation methodology. These articles provide examples and practical information for improvement efforts.


IMPROVING HEALTH CARE SERIES, PART 4: CONCEPTS FOR IMPROVING ANY CLINICAL PROCESS. This article offers a method for designing changes for improved outcomes and lowered costs. It is the fourth article in a five-part series examining the process of quality and value improvement. Batalden, B., Mohr, J., Nelson, E., & Plume, S. (1996). The Joint Commission Journal on Quality Improvement, 22 (10), 651 – 659.

BREAST CANCER METHODS. This paper discusses measurement parameters to assess quality in breast cancer treatment programs. Citing patient satisfaction, survivorship, and accountability, the authors advocate the use of three data collection tools: patient surveys, administration and claims data, and cancer registries. An example of a patient satisfaction survey is included. Foundation for Accountability. (1996, Fall). Portland, OR: Author.

IMPROVING HEALTH CARE SERIES, PART 3: CLINICAL BENCHMARKING FOR BEST PATIENT CARE. This article describes the theory of benchmarking. Three steps in the process include tension for change, building awareness of local capability versus best-known capability, and encouraging people to move from a position of inertia to positive action. A step-by-step process is described and worksheet samples are given. Mohr, J., Mahoney, C., Nelson, E., Batalden, P., & Plume, S. (1996.) The Joint Commission Journal on Quality Improvement, 22 (9), 599 – 616.

IMPROVING HEALTH CARE SERIES, PART 1: THE CLINICAL VALUE COMPASS. This is the first article in the Improving Healthcare Series. It describes quality improvement in terms of four compass points of value: functional, satisfaction, cost, and clinical. Directions are given for developing and studying a topic in terms of these values. Nelson, E., Mohr, J., Batalden, P., & Plume, S. (1996). The Joint Commission Journal on Quality Improvement 22 (4), 243 – 258.

IMPROVING HEALTH CARE SERIES, PART 2: A CLINICAL IMPROVEMENT WORKSHEET AND USER’S MANUAL. This article uses both the clinical value compass discussed in the first article of this series, as well as the Plan-Do-Study-Act (PDSA) cycle. A clinical improvement worksheet is given along with an example PDSA cycle for improving the surgical treatment of carpal tunnel syndrome. Nelson, E., Batalden, P., Plume, S. & Mohr, J. (1996). The Joint Commission Journal on Quality Improvement 22 (8), 531 – 548.
MEASURING HEALTH CARE QUALITY: BREAST CANCER. This paper presents a summary of commonly used quality measures for breast cancer focusing on the following areas: health outcomes, disease progression or management, performance of essential care processes, disruption to patient or family routine, and satisfaction with care. The author also provides recommendations for measurement of health outcomes, including quality of life, and recommendations for outcomes for processes of care. U. S. Department of Health and Human Services. (1996). (AHCPR Publication No. 96-N020). Rockville, MD: Author.

Measuring Patient Perception of Disease, Information Needs, and Mental Health Status

This section describes how clinicians measure patients' understanding and awareness of the changes in their health status, and the techniques they use in administering these measures. It also explores how the risk of psychosocial trauma relating to breast cancer is assessed and understood.

Basic steps include understanding the sorts of parameters that patients use to assess their own health as well as the degrees of psychosocial risk. Authors discuss the types of cultural awareness needed by researchers in producing and conducting studies. Also discussed are the best times to assess changes in health and functional status and the reliability of data from these measures. These tools are useful when developing patient navigation and support service referral protocols.

RELIABILITY AND VALIDITY OF BREAST CANCER SCREENING BELIEF SCALES IN AFRICAN AMERICAN WOMEN. The purpose of this study was to describe the development of culturally sensitive scales to measure beliefs related to mammography and breast self-examination screening. These scales may be useful for screening low-income African-American women to develop tailored interventions to increase breast cancer screening. Champion, V. L. & Scott, C. R. (1997). Nursing Research, 46 (6), 331 – 337.


ASSESSING PROBLEMS OF CANCER PATIENTS: PSYCHOMETRIC PROPERTIES OF THE CANCER INVENTORY OF PROBLEM SITUATIONS. This study evaluated the psychometric properties of the Cancer Inventory of Problem Situations (CIPS). This is a cancer-specific survey instrument designed to assess day-to-day problems and rehabilitation needs of cancer patients. The authors indicate that a cancer-specific instrument will lead to better documentation of problems, better assessment of individuals, and therefore, to more appropriate interventions. Schag, C.A., Heinrich, R. L., Aadland, R. L. & Ganz, P. A. (1990). Health Psychology, 9 (1), 83 – 102.
CHARACTERISTICS OF WOMEN AT RISK FOR PSYCHOSOCIAL DISTRESS IN THE YEAR AFTER BREAST CANCER. This article provides a description of rehabilitation problems of women considered to be either low risk or at risk for psychosocial morbidity. Women diagnosed with stage I and II breast cancer were studied twice: in the first month after their diagnosis and one year after primary treatment. The authors used the Cancer Rehabilitation Evaluation System (CARES) to develop a detailed listing of rehabilitation needs. Examples derived from this study’s listing of needs may be helpful to clinicians in their interactions with patients. Schag, C. A., Ganz, P. A., Polinsky, M. L., Fred, C., Hirji, K. & Petersen, L. (1993). Journal of Clinical Oncology, 11 (4), 783 – 793.


Measuring Patient Reaction to Symptoms and Self-Management

The degree to which patients can manage their symptoms will determine their morbidity and survivorship. Self-assessment is especially important given the increasing use of outpatient services to treat breast cancer. How do clinicians evaluate the level of debilitation that individual patients experience, and how can treatment programs be managed in ways that are sensitive to the differing needs of patients? The tools described in the following articles can be useful when considering changes in treatment protocols and/or cancer center development.

MEASUREMENT OF FATIGUE IN CANCER PATIENTS: DEVELOPMENT AND VALIDATION OF THE FATIGUE SYMPTOM INVENTORY. This study describes a systematic study of the affect of fatigue on cancer patients. The primary aim of this study was to test a newly developed measure of fatigue for use with cancer patients—the Fatigue Symptom Inventory (FSI). This 13-item self-report measure was designed to evaluate the intensity and duration of fatigue and its impact on quality of life. Hann, D. M., Jacobsen, P. B., Azzarello, L. M., Martin, S. C., Curran, S. L., Fields, K. K., Greenberg, H. & Lyman, G. (1998). Quality of Life Research, 7 (4), 301 – 310.

THE RAND 36-ITEM HEALTH SURVEY 1.0. This article describes the RAND 36-item Health Survey 1.0 and includes a copy of the instrument. The survey profiles eight health concepts: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, general mental health, social functioning, energy/fatigue, and general health perceptions. It also includes a single item that provides an indication of perceived change in health. Hays, R. D., Sherbourne, C. D. & Mazel, R. M. (1993). Health Economics, 2 (3), 217 – 227.
THE MOS 36-ITEM SHORT-FORM HEALTH SURVEY (SF-36). I. CONCEPTUAL FRAMEWORK AND ITEM SELECTION. A 36-item short form (SF-36) was constructed to survey health status in the Medical Outcomes Study. The SF-36 includes one multi-item scale that assesses eight health concepts: limitations in physical activities because of health problems; limitations in social activities because of physical or emotional problems; limitations in usual role activities because of physical health problems; bodily pain; general mental health (psychological distress and well-being); limitations in usual role activities because of emotional problems; vitality (energy and fatigue); and general health perceptions. The Medical Outcomes Study (MOS) survey was constructed for self-administration by persons 14 years of age and older and for administration by a trained interviewer in person or by telephone. Ware, J. E. & Sherbourne, C. D. (1992). Medical Care, 30 (6), 473 – 483.

Measuring Quality of Life

Cancer patients are living for extended periods of time. They cope with chronic effects of cancer and its treatment that can affect all areas of functioning: physical, psychological, social, and vocational. Moreover, cancer survival gains are often accomplished through use of toxic or debilitating treatments that may have life-long consequences for the patient.

Research and clinical efforts have been directed toward understanding cancer patients’ rehabilitation needs and subsequent quality of life. Quality of life and outcome assessments are particularly critical in assessing clinical care for diseases such as cancer because of potential mortality and the exacting modalities of treatment.

These articles discuss quality of life measures in the context of different types of hospitals and treatment centers. Quality of life is also examined within the parameters of clinical trials.

THE EUROPEAN ORGANIZATION FOR RESEARCH AND TREATMENT OF CANCER QLQ-C30: A QUALITY-OF-LIFE INSTRUMENT FOR USE IN INTERNATIONAL CLINICAL TRIALS IN ONCOLOGY. The QLQ-C30, the current core questionnaire for evaluating the quality of life of patients participating in international clinical trials in oncology, is described. It incorporates nine multi-item scales: five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), and a global health and quality-of-life scale. The reported reliability and validity of the questionnaire were highly consistent across the three linguistic and cultural groups studied – patients from English-speaking countries, northern Europe, and southern Europe. Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechertn, H., Fleishman, S. B., de Haes, J. C., et al. (1993). Journal of the National Cancer Institute, 85 (5), 365 – 376.

THE FUNCTIONAL ASSESSMENT OF CANCER THERAPY SCALE: DEVELOPMENT AND VALIDATION OF THE GENERAL MEASURE. The authors developed and pilot-ed a 33-item general cancer quality-of-life (QL) measure for evaluating patients receiving cancer treatment, called the Functional Assessment of Cancer Therapy (FACT) scale. An adaptation of the FACT scale is a self-administered test intended for use in clinical trials.

ASSESSMENT OF QUALITY OF LIFE INDICATORS AMONG SELECTED PATIENTS IN A COMMUNITY CANCER CENTER. In this research cancer patients were assessed with the Health Status Questionnaire (HSQ). The authors report that breast cancer respondents scored 16.61% lower than the normative values for individuals less than 65 years of age, whereas prostate cancer respondents scored 10.91% higher than the normative values for those older than 65. The data analysis confirmed that breast cancer and prostate cancer patients have statistically different scores on the HSQ, implying different quality of life concerns for each group. Frazer, G. H., Brown, C. H. & Graves, T. K. (1998). Issues in Mental Health Nursing, 19 (3), 241 – 262.

BASE-LINE QUALITY-OF-LIFE ASSESSMENT IN THE NATIONAL SURGICAL ADJUVANT BREAST AND BOWEL PROJECT BREAST CANCER PREVENTION TRIAL. This article explores the feasibility of collecting health-related quality-of-life data in a large, multicenter, chemoprevention trial for women at high risk of breast cancer. The integration of health-related quality-of-life data collection into this clinical trial indicates that it could be used as a safety-monitoring end point and as an explicit and measurable outcome for the entire trial. Ganz, P. A., Day, R., Ware, J. E., Redmond, C. & Fisher, B. (1995). Journal of the National Cancer Institute, 87 (18), 1372 – 1382.

QUALITY OF LIFE AS AN ENDPOINT IN EORTC CLINICAL TRIALS. For more than a decade, the European Organization for Research and Treatment for Cancer (EORTC) has included quality of life as an outcome measure in some of its trials. This paper provides an overview of the types and the design of studies, data management of quality of life assessment, compliance, missing data, and lessons learned during the past years with respect to QOL assessments in the EORTC studies. Kiebert, G. M., Curran, D. & Aaronson, N. K. (1998). Statistics in Medicine, 17 (5-7), 561 — 569.


Measuring Patient Satisfaction

How do patients assess the quality of health care that they receive? This section outlines various methods to assess patient satisfaction and the usefulness of such measures for health service evaluation and improvement.

PATIENT EVALUATION OF CARE WITHIN A MULTI-DISCIPLINARY BREAST CARE CENTER. This article is a discussion of patient satisfaction as reported in a survey instrument utilized at the University of Michigan Breast Care Center. The effect of multidisciplinary care, including factors such as medical thoroughness, staff concern, and length of wait-

PATIENT-BASED QUALITY MEASUREMENT SYSTEMS. The authors state that patient-based measurement systems can provide direct measures of successes and failures, strengths, weaknesses, and changes in the provider’s capacity to produce health outcomes at a cost that represents value. This article provides: design principles to guide the development of patient-based measurement systems; a specific, yet flexible method for designing and testing patient-based measurement systems; and real-world examples of patient-based systems. Nelson, E. C. & Batalden, P. B. (1993). Quality Management in Health Care, 2 (1), 18 – 30.

INFORMATION SYSTEMS/DATA MANAGEMENT

Data Used in Screening

Computerized administrative and clinical files are increasingly used to assist in the cancer screening process. Articles in this section explain how facilities of various sizes and geographic locations can make use of tracking systems. The authors also discuss utilization of tracking systems by physicians and other health care staff.

HOSPITAL INFORMATION SYSTEMS AND PATTERNS OF CANCER SCREENING. Attempts at determining the referral patterns for cancer screening at a large county hospital and some of the challenges to that process are reported here. To enhance capabilities of computerized health information systems, the following principles are discussed: complete coverage, uniform collection of data across time and files, and inclusion of linking capabilities. Nasseri, K., Bastani, R., Bernstein, S. & Breslow, L. (1994). Journal of Medical Systems, 18 (6), 335 – 342.

COMPUTERIZED PROMPTS FOR CANCER SCREENING IN A COMMUNITY HEALTH CENTER. This article describes the implementation and subsequent use of a computerized health maintenance tracking system in a large urban community health center as part of a larger study designed to increase rates of mammography and other screening procedures in low-income African-Americans. It found that computer-promoting systems could be useful in a community health center. Yarnall, K. S., Rimer, B. K., Hynes, D., Watson, G., Lyna, P. R., Woods-Powell, C. T., Terrenoire, J. & Barber, L. T. (1998). Journal of the American Board of Family Practitioners, 11 (2), 96 – 104.
Data Used in Treatment

This section outlines how data within administrative records can help to streamline processes and cut down on waste. Authors have written on ways that data use can tell which practices may be most cost effective and least debilitating to the patient.

YOUR CANCER REGISTRY CAN INCLUDE QUALITY-OF-LIFE, ADMINISTRATIVE, AND EXTENDED CLINICAL DATA. The authors of this article discuss the National Cancer Data Base (NCDB) used to collect information on malignancies for cancer registries. They state that the NCDB core data can be expanded to include other data elements that can be useful in planning, funding, and quality improvement. The authors encourage administrative support for space, equipment and staffing, clinician compliance with reporting, and increased education on the purpose and value of registry information. Cartwright-Alcarese, F. & Facciponti, C. (1996). Oncology Nursing Forum, 23 (6), 973.


Information Systems and Internal Communications

Physicians providing consultations regarding the diagnosis and management of cancer patients are using telemedicine. Collaborative associations between academic medical centers and community hospitals can use telemedicine to promote and enhance cancer treatment and clinical research.

THE IMPLEMENTATION OF TELEMEDICINE WITHIN A COMMUNITY CANCER NETWORK. This article describes the technology employed for the telemedicine systems at the Jefferson Cancer Network which were chosen to meet three related specifications: low capital and operating cost, internal maintainability by community hospital data processing staff, and compatibility with the existing technology infrastructure. London, J. W., Morton, D. E., Marinucci, D., Catalano, R. & Comis, R. L, (1997). Journal of the American Medical Informatics Association, 4 (1), 18 – 24.

A SYSTEM OF TELE-ONCOLOGY AT THE UNIVERSITY OF WISCONSIN HOSPITAL AND CLINICS AND REGIONAL ONCOLOGY AFFILIATE INSTITUTIONS. This paper describes a system in evolution that provides regional oncology services at the University of Wisconsin Hospital and Clinics and regional oncology affiliates. Stitt, J. A. (1998). Wisconsin Medical Journal, 97 (1), 38 – 42.
Patient Characteristics

This section examines outreach, education, and treatment issues for populations and ethnic groups for whom breast cancer treatment has been difficult. Research has been included based on availability and date of publication. Issues that have been raised for one group may be useful for populations where research is not currently available.

GENERAL CULTURAL ISSUES

ATTITUDES ABOUT BREAST CANCER AND MAMMOGRAPHY: RACIAL, INCOME, AND EDUCATIONAL DIFFERENCES. This study examines racial differences in perceived barriers to mammography and findings about the knowledge differences related to race, income, and education. Miller, A. M. & Champion, V. L. (1997). Women-Health, 26 (1) 41 – 63.


CULTURALLY COMPETENT NURSING CARE RELATED TO BREAST CANCER. This article provides an overview of elements of African-American, Asian-American, Latino/Hispanic Americans, and Native American cultures as issues to consider in planning culturally competent breast cancer programs. Life stresses, health beliefs and practices, communication styles, customs, and family issues are addressed. Ott, C. (1997). Nebraska Nurse, 30 (3), 31.

MINORITY WOMEN AND BREAST CANCER SCREENING: THE ROLE OF CULTURAL EXPLANATORY MODELS. This paper provides an understanding of the use of breast cancer screening among minority women by drawing attention to the role of women’s cultural explanatory models (CEMs). CEMs stem from the sociocultural context and involve cultural beliefs and values, personal life experiences, and both biomedical and popular explanations of health and illness. This paper discusses suggestions for addressing these issues in an effort to improve breast cancer screening rates through adopting a culturally relativistic approach. Rajaram, S. S. & Rashidi, A. (1998). Preventive Medicine, 27 (5, Pt. 1), 757 – 764.
AFRICAN-AMERICANS


RACIAL DIFFERENCES IN SURVIVAL FROM BREAST CANCER. RESULTS OF THE NATIONAL CANCER INSTITUTE BLACK/WHITE CANCER SURVIVAL STUDY. This study examined the ability of recognized predictive factors for breast cancer to account for lower observed survival in blacks compared with whites. The study found that approximately 75% of the racial difference in survival were explained by the predictive factors studied. Eley, J. W., Hill, H. A., Chen, V. W., Austin, D. F., Wesley, M. N., Muss, H. B., Greenberg, R. S., Coates, R. J., Correa, P., Redmond, C. K., et al (1994). Journal of the American Medical Association, 272 (12), 947 – 954.

THE MEANING OF RACE IN CANCER OF THE BREAST. The author states that compared with white women, black women have a lower incidence of breast cancer but a higher mortality rate. This article comments on studies indicating that when quality of care is comparable, stage of disease at time of treatment determines outcome rather than biological differences that some studies have attributed to race. Freeman, H. P. (1997). The Cancer Journal from Scientific American, 3 (2), 76 – 77.

CANCER OF THE BREAST IN POOR BLACK WOMEN. The authors carried out a retrospective analysis of 708 patients (94% black) with breast cancer who were diagnosed, treated, and/or followed at Harlem Hospital Center (New York) between 1964 and 1986. Nearly all of the patients were of low economic status with almost 50% having no medical coverage. The authors state that breast cancer survival in this population of poor black women is low compared to the survival rate of black women nationally and very low compared to white women. Freeman, H. P. & Wasfie, T. J. (1989). Cancer, 63 (12), 2562 – 2569.

CULTURAL BARRIERS TO CANCER SCREENING AMONG AFRICAN AMERICAN WOMEN: A CRITICAL REVIEW OF THE QUALITATIVE LITERATURE. This article examines the influence of cultural factors in the success or failure of interventions. Women who were surveyed for the study stated that they placed personal preventive screening behaviors on a low priority in the context of other family health priorities; and that female friends, relatives, and social networks were important in the flow of cancer information. Hoffman-Goetz, L. & Mills, S. L. (1997). Women and Health, 3 (3-4), 183 – 201.

ASIAN-AMERICANS


VARIABLES ASSOCIATED WITH BREAST SELF-EXAMINATION AMONG CHINESE WOMEN. Asians are among the fastest growing minorities in the U. S. The purpose of this study was to identify barriers to Breast Self-Examination (BSE) among Chinese women. Implications for nursing interventions that foster competence in BSE in this population are suggested. Zxy-yann, J. L. (1995). Cancer Nursing, 18 (1), 29 – 34.

JEWISH HERITAGE

JEWISH RELIGION AND RISK OF BREAST CANCER. The authors investigated whether an increased risk of breast cancer among Jewish women is confined to those with a family history of the disease. The study found that overall, Jewish women had only a slightly raised relative risk of breast cancer compared to non-Jewish women. These results are consistent with data suggesting that certain groups of Jewish women have a higher than expected rate of mutation in the breast-cancer gene BRCA 1. Egan, K. M., Newcomb, P. A., Longnecker, M. P., Trentham-Dietz, A., Baron, J. A., Trichopoulos, D., Stampfer, M. J. & Willett, W. C. (1996). Lancet, 347 (9016), 1645 – 1646.

BRCA1/BRCA2 MUTATIONS AND BREAST CANCER IN ASHKENAZI JEWISH WOMEN. The authors tested Ashkenazi Jewish women with breast or ovarian cancer for genetic mutations to develop genetic screening criteria. Based on their findings the authors determined that BRCA 1 and 2 gene testing can be an accurate predictor for women with a positive family history of cancer. These genes can also be predictors for those in whom breast cancer develops before age 45, with or without a family history of breast cancer. Gilbert, F., Dahney, M. K., Diemer, K., Ludwig, S., Rosenthal, G. & Osborne, M. P. (1997). Annals of the New York Academy of Sciences, 833, 198 – 203.

LATINO HERITAGE

BREAST CARE AMONG LATINO IMMIGRANT WOMEN IN THE U.S. This study was conducted in a large urban area in the Midwest of the United States to identify factors associated with breast care in Latino immigrant women. It found that limited knowledge about breast care, unemployment, and short period of residence in the U. S. were all related to inadequate breast care in this group of women. Peragallo, N. P., Fox, P. G. & Alba, M. L. (1998). Health Care for Women International, 19 (2), 165 – 172.
MEXICAN-AMERICANS

BARRIERS TO CANCER SCREENING IN MEXICAN-AMERICAN WOMEN. This study tests the simultaneous effect of various predictors of breast and cervical cancer screening in a low-income, Mexican-American population. It found that knowledge of cancer was positively, rather than negatively, associated with anxiety about cancer. The authors recommend that cancer screening programs for Mexican-American women address access barriers, communication skills, knowledge, and anxiety. Lobell, M., Bay, R. C., Rhoads, K. V. & Keske, B. (1998). Mayo Clinical Proceedings, 73 (4), 301 – 308.

PAP SMEAR AND MAMMOGRAM SCREENING IN MEXICAN-AMERICAN WOMEN: THE EFFECTS OF ACCULTURATION. This study found that the two-year prevalence of Pap smear and mammogram screening among Mexican-Americans increased with each gain in English proficiency and use. However, these associations disappeared when adjusted for age, income, insurance, and education. The author concluded that a strong traditional Mexican attitude toward family was positively related to mammography use and could be utilized to increase the effectiveness of cancer control interventions in Mexican-Americans. Suarez, L. (1994). American Journal of Public Health, 84 (5), 742 – 746.

FUNCTIONAL AND PHYSICAL DISABILITIES

BREAST AND CERVICAL CANCER SCREENING AMONG WOMEN WITH PHYSICAL DISABILITIES. This article presents comparative rates of screening for breast and cervical cancer in women with a variety of physical disabilities and a comparison group of women without disabilities. The authors state that women with physical disabilities may be at a higher risk for delayed diagnosis of breast and cervical cancer due to environmental, attitudinal, and information barriers. Nosek, M. A. & Howland, C. A. (1997). Archives of Physical Medicine and Rehabilitation, 78 (12, Suppl. 5), S39 — S44.

USE OF CERVICAL AND BREAST CANCER SCREENING AMONG WOMEN WITH AND WITHOUT FUNCTIONAL LIMITATIONS – UNITED STATES, 1994-1995. National data on breast and cervical cancer screening for women with disabilities is limited. This report provides findings indicating that women with functional limitations (FLs) were less likely than women without FLs to have had a Pap test within the previous three years. Similarly, women over 65 with three or more FLs were less likely to have ever had a mammogram compared with similarly aged women with no limitations. U. S. Department of Health and Human Services. (1998). Morbidity and Mortality Weekly Report, 47 (40), 853 – 856. [On-line]. Available: http://www.cdc.gov/epo/mmwr/preview/mmwrhtml/00055280.htm

LESBIAN LIFESTYLE

BREAST CANCER AND WOMEN PARTNERING WITH WOMEN. The Center for Disease Control has targeted women who are lesbians as an under-served group for outreach efforts. This article discusses barriers that can exist for lesbian women who are accessing and utilizing comprehensive health care with a focus on breast cancer treatment. Ott, C. & Eilers, J. (1997). Nebraska Nurse, 30 (3), 29.
BREAST AND CERVICAL CANCER AMONG LESBIANS. This article states that lesbians appear to be less likely to receive routine screening for breast and cervical cancer than recommended by routine standards of care. They may therefore be at risk of increased morbidity and mortality resulting from delayed diagnosis and treatment. The author provides an overview of breast health care among lesbians and identifies strategies to assist this population in terms of research, public education, and clinical training. A list of lesbian cancer resources is included. Rankow, E. J. (1995). *Womens Health Issues, 5*(3), 123 – 129.

MALE BREAST CANCER PATIENTS

BREAST CANCER AMONG MEN: RAISING AWARENESS FOR PRIMARY PREVENTION. The authors state that the clinical picture of breast cancer among men resembles that seen in women and the mortality rate is also similar. They present guidelines for male patient education, health screening, and patient support. Fullerton, J. T., Lantz, J. & Sadler G. R. (1997). *Journal of the American Academy of Nurse-Practitioners, 9*(5), 211 – 216.

PATIENT AGE

AGE-RELATED DIFFERENCES IN BREAST CANCER STAGE AT DIAGNOSIS BETWEEN BLACK AND WHITE PATIENTS IN AN URBAN COMMUNITY HOSPITAL. This study evaluated stage distribution relative to age among black and white breast cancer patients. It found age-related differences in breast cancer stage distribution between black and white patients which appeared independent of socioeconomic status. The authors endorse more aggressive screening and public education programs directed toward younger black women. Newman, L. A. & Alfonso, A. E. (1997). *Annals of Surgical Oncology, 4*(8), 655 – 662.

AGE-RELATED DIFFERENCES IN BREAST CANCER TREATMENT. More than half of the cases of breast cancer treated in the United States occur in women over age 65. Investigators have demonstrated that the use of aggressive therapies is less frequent in the care of breast cancer in older women than in similarly affected younger women. This study states that although age-related patient preferences and comorbidity are relevant, the age-related attitudes of caregivers helps to explain these variations. August, D. A. Rea, T. & Sondak, V. K. Ann (1994). *Annals of Surgical Oncology, 1*(1), 45 – 52.

HEALTH STATUS AND MAMMOGRAPHY USE AMONG OLDER WOMEN. This study assessed the extent to which an age-associated reduction in mammography use can be explained by declining self-reported health status. It concluded that the observed decline in recent mammography use with advancing age was not explained by variation in health status. Because healthy, elderly women may live long enough to realize the potential benefit of screening mammography, factors responsible for its reduced use could be identified. Burack, R. C., Gurney, J. G. & McDaniel, A. M. (1998). *Journal of General Internal Medicine, 13*(6), 366 – 372.
THE EFFECT OF AGING ON THE UTILIZATION OF CHEMOTHERAPY FOR METASTATIC BREAST CANCER: A POPULATION-BASED STUDY. This article states that women 65 and older receive less adjuvant chemotherapy than younger women, in part because chemotherapy has been less effective in postmenopausal than premenopausal women in clinical trials. Metastatic breast cancer, however, does not respond differently to chemotherapy by age. This article examines how less frequent utilization of chemotherapy in older patients may be caused by a combination of patient and physician factors and may result in less effective treatment. Fetting, J. H., Comstock, G. W., Eby, S., Huelskamp, A. M., Sullivan, S. A., Zahurak, M., Gerber, J., Kass, F. H. & Smith, R. (1997). Cancer Investigation, 15 (3), 199 – 203.


ACCEPTABILITY OF MOBILE MAMMOGRAPHY AMONG COMMUNITY-DWELLING OLDER WOMEN. This study tested the acceptability of mobile mammography among community-dwelling older women and tried to identify factors predictive of mobile mammography acceptance. It found that mobile mammography is acceptable to many older, community-dwelling women and may substantially increase screening for some groups. Levin, J. R., Hirsch, S. H., Bastani, R., Ganz, P. A., Lovett, M. L. & Reuben, D. B. (1997). Journal of the American Geriatric Society, 45 (11), 1365 – 1370.

THE INFLUENCE OF OLDER AGE ON BREAST CANCER TREATMENT DECISIONS AND OUTCOME. The purpose of this study is to identify factors that influence breast cancer treatment decisions and determine if women age 65 and older are treated differently than younger women. The study found that older patients have significant treatment differences as compared to younger patients. Despite these differences, however, similar local control and survival were achieved at five to ten years. With the expected survival of older women increasing, the prospective evaluation of treatment options for older women can be considered. Merchant, T. E., McCormick, B., Yahalom, J. & Borgen, P. (1996). International Journal of Radiation Oncology, Biology, Physics, 34 (3), 565 – 570.

PREVALENCE AND CORRELATES OF BREAST AND CERVICAL CANCER SCREENING AMONG OLDER WOMEN. This paper investigates the relationship between physician recommendation and mammography use among older women. It states that decreased screening in older age groups may be attributed to lack of physician recommendations. Ruchlin, H. S. (1997). Obstetrics and Gynecology, 90 (1), 16 – 21.
SOCIO-ECONOMIC STATUS


SOCIAL EPIDEMIOLOGY AND THE FUNDAMENTAL CAUSE CONCEPT: ON THE STRUCTURING OF EFFECTIVE CANCER SCREENS BY SOCIOECONOMIC STATUS. This study examines the social distributions of two cancer screening tests – Pap smears and mammography. It found a consistent association between indicators of socioeconomic status and recent screening. The authors concluded that women of lower socioeconomic status were less likely to access screening and therefore more likely to have cancer diagnosed later with a less favorable diagnosis. Link, B. G., Northridge, M. E., Phelan, J. C. & Ganz, M. L. (1998). *Milbank Quarterly, 76* (3), 375 — 402, 304 – 305.

BREAST CANCER RESCREENING IN LOW-INCOME WOMEN. This study examined factors associated with repeat screening for low-income women enrolled in a free breast and cervical cancer-screening program. Repeat screening differed by age groups, race/ethnicity, level of education, foreign born status, history of previous mammography, and enrollment clinic. The study suggested that in addition to initial efforts for enrollment, screening programs should emphasize repeated screening especially for women with certain demographic and screening history characteristics. Song, L. & Fletcher, R. (1998). *American Journal of Preventative Medicine, 15* (2), 128 – 133.

DO VOUCHERS IMPROVE BREAST CANCER SCREENING RATES? RESULTS FROM A RANDOMIZED TRIAL. This article examines the effect of distributing a voucher for free mammography on compliance with mammography screening guidelines. Its results indicate that adding free screening to community and physician educational interventions appears to be effective in increasing the use of mammography, especially with women who do not get screened and women who are financially vulnerable. Stoner, T. J., Dowd, B., Carr, W. P., Maldonado, G., Church, T. R. & Mandel, J. (1998). *Health Services Research, 33* (1), 11 – 27.

MAMMOGRAPHY SCREENING: HOW IMPORTANT IS COST AS A BARRIER TO USE? This article examines the role of economic variables, including insurance coverage, in the use of mammography among women aged 50 to 75. This analysis supports the view that the key to use of mammography among these women is referral by a physician. The authors found no evidence that the effect of improved insurance coverage would be greater use of mammography among low-income women. Urban, N., Anderson, G. L. & Peacock, S. (1994). *American Journal of Public Health, 84* (1), 50 – 55.

OUTREACH AND EDUCATION ON BREAST HEALTH AND CANCER TREATMENT

General Cancer Information

The annual detected incidence of breast cancer among women increased approximately 52% during 1950-1990, while the death rate increased 4% during the same period. It is estimated that 175,000 new invasive cases of breast cancer in women and 1,300 new cases of breast cancer in men will be diagnosed in the U. S. in 1999, and that 43,700 deaths (43,300 women, 400 men) will occur.

CANCER UNDEFEATED. This study found that observed changes in mortality due to cancer primarily reflect changing incidence or early detection. The authors conclude that the most promising approach to the control of cancer is a national commitment to prevention, combined with a rebalancing of the focus and funding of research. Bailar, III, J. & Gornik, H. L. (1997). The New England Journal of Medicine, 336 (22), 1569 – 1574.


Available: http://www.cdc.gov/epo/mmwr/preview/mmwrhtml/00043942.htm
BREAST CANCER CARE COMMUNICATION

Program Planning

Planning is one of the most important administrative tasks for an integrated breast cancer program. Areas in this section include ways that patients are introduced to cancer care, and the usefulness, social appropriateness, and appealing nature of communications. Patient need may be anticipated in an empathetic way that crosses all levels of their care. How effectively this is done is a function of knowing what is available and planning well.


MULTILINGUAL HEALTH EDUCATION RESOURCE GUIDE (2nd ed.) The purpose of this guide is to bring together health education materials for limited-English speaking adults in the United States and make them available to health care providers through a single dissemination source. The guide includes breast health resources in 10 languages. Center for Applied Linguistics (1996). Washington, DC: Author.

HOW TO PLAN YOUR COMMUNICATIONS STRATEGY FOR BREAST AND CERVICAL CANCER: A GUIDE FOR COMMUNITY LEADERS. This guide was developed as a resource to use in a communications campaign to combat breast and cervical cancer in Hispanic communities. It presents communications strategies that health organizations can apply to social marketing efforts. Bilingual. HMA Associates. (1995). Washington, DC: Author.

Computers as Patient Education Tools

The convergence of computers, television, and telecommunications in one information superhighway means that patients receive information from many sources. How can these new technologies be used most effectively? Will patients use technologically based programs if they have the opportunity?


AN INTERACTIVE COMPUTER PROGRAM FOR EDUCATING AND COUNSELING PATIENTS ABOUT GENETIC SUSCEPTIBILITY TO BREAST CANCER.
Interactive computer programs can be used to supplement health education. The authors describe their experience developing an interactive CD-ROM on gene testing and breast cancer, and respond to anticipated criticisms of this technology. Green, M. J. & Fost, N. (1997). Journal of Cancer Education, 12 (4), 204 – 208.

IMPACT OF A PATIENT-CENTERED, COMPUTER-BASED HEALTH INFORMATION/SUPPORT SYSTEM. This study found that patients given in-home access to computers use the system, improve their quality of life, and use medical services more efficiently. Gustafson, D. H., Hawkins, R., Boberg, E., Pingree, S., Serlin, R. E., Graziano, F. & Chan, C. L. (1999). American Journal of Preventative Medicine, 16 (1), 1 – 9.

Patient Communications and Literacy
The most poorly educated adults have the lowest literacy levels and experience the highest rates of morbidity and mortality from chronic diseases and conditions. Innovative intervention ideas and strategies can be used to reach audiences who are not benefiting from current health communication efforts.


MATERIALS AND STRATEGIES THAT WORK IN LOW LITERACY HEALTH COMMUNICATION. This article focuses on solutions to the well-documented problem of health information materials that cannot be read or comprehended by low literacy adults. Plimpton, S. & Root, J. (1994). Public Health Reports, 109 (1), 86 – 92.

Socio-Economic and Cultural Issues
Members of certain cultural groups may perceive health education materials designed for the general population as unclear, irrelevant, or unattractive. This section describes ways to increase knowledge about breast cancer and to improve preventive health care among minority and medically underserved women. How women of lower socio-economic status view mammography and communicate with their primary care providers about breast screening are also discussed.

BREAST SCREENING BEHAVIOR AND INTERACTIONS WITH HEALTH CARE PROVIDERS AMONG LOWER INCOME WOMEN. The authors found that physician-patient discussion in primary care settings is associated with lower income women getting mammograms regularly, and that the physician’s enthusiasm for mammography is a particularly important factor. Mickey, R. M., Vezina, J. L., Worden, J. K. & Warner, S. L. (1997). Medical Care, 35 (12), 1204 –1211.
A CANCER-PREVENTION INTERVENTION FOR DISADVANTAGED WOMEN: DESIGN AND IMPLEMENTATION. This article describes a two-hour psycho-educational intervention that was developed as a culturally sensitive curriculum in English and Spanish-language versions for home health care attendants. Morgan, C. & Levin, G. (1995). *Journal of Cancer Education, 10* (3) 168 – 175.

PRINTED HEALTH EDUCATION MATERIALS FOR DIVERSE COMMUNITIES: SUGGESTIONS LEARNED FROM THE FIELD. This study presents developmental strategies for health education materials targeted to multicultural populations. Cultural factors that should be considered when designing printed materials are illustrated, and steps in the design of culturally appropriate materials are outlined. Sabogal, F., Otero-Sabogal, R., Pasick, R. J., Jenkins, C. N. H. & Perez-Stable, E. J. (1996). *Health Education Quarterly, 23* (Supplement), 123 – 141.

Communication with Elderly Patients

Breast cancer screening rates continue to lag for older women, especially those older than 65 years. Among older minority women in urban areas, for whom breast cancer risk is high and access to screening low, both social supports and breast cancer knowledge have been linked to mammography use. Physician communication is one of the keys to older patients’ acceptance of screening.

THE IMPORTANCE OF PHYSICIAN COMMUNICATION ON BREAST CANCER SCREENING OF OLDER WOMEN. This study considered race, age, health status, and physician-patient communication as variables influencing breast cancer screening utilization rates for women older than 65. It found that communication and access significantly predicted a recent mammogram or clinical breast examination. Fox, S. A., Siu, A. L. & Stein, J. A. (1994). *Archives of Internal Medicine, 154* (18), 2058 – 2067.

INTERACTION BETWEEN THE PHYSICIAN AND THE OLDER PATIENT: THE ONCOLOGIST’S PERSPECTIVE. This article discusses the oncologist’s perspective regarding communication with older cancer patients. The author states that decision-making about the treatment of these patients should be influenced by physiologic, not chronologic, age and that it is critical to consider quality rather than quantity of life. Ganz, P. A. (1997). *Cancer, 80* (7), 1323 – 1325.

Patient Preferences in Communications

Rising health care costs and greater emphasis placed on self-care has increased the need for patient involvement in medical decision making. In breast cancer treatment, understanding patient need for cancer-related information is important when supporting patient involvement in decision making. The articles in this section review the degree of involvement women with breast cancer want in medical decision making. Also discussed are the types of information women judge to be most important.


BREAST CANCER CARE: WOMEN’S EXPERIENCE. This article illustrates the importance of considering the psychosocial care of patients in breast cancer care. It suggests areas where health care systems may be modified to address the psychosocial needs of women. Bottomley, A. & Jones, L. (1997). European Journal of Cancer Care, 6 (2), 124 – 132.


THE ROLE OF THE BREAST CLINIC NURSE. This article addresses the breast clinic nurse’s role in meeting the emotional and informational needs of women scheduled for breast biopsy procedures. The human response to illness model is used as a framework for understanding the phenomenon of anxiety within this context. Deane, K. A. (1997). Association of Operating Room Nurses Journal, 66 (2), 304 – 310.


WHY DO WOMEN’S ATTITUDES TOWARD MAMMOGRAPHY CHANGE OVER TIME? IMPLICATIONS FOR PHYSICIAN-PATIENT COMMUNICATION. This is a study of interventions designed to promote breast cancer screening. It recognizes that a woman may react to mammography information provided by people in her social network. The authors state that women may also reach out to others as advocates of breast cancer screening, thereby reinforcing or changing others’ opinions or behavior as well as their own. Pearlman, D. N., Rakowski, W., Clark, M. A., Ehrich, B., Rimer, B. K., Goldstein, M. G., Woolverton, H. & Dube, C. E. (1997). *Cancer Epidemiology, Biomarkers and Prevention*, 6 (6), 451 - 457.


SURVEY OF BREAST CANCER PATIENTS CONCERNING THEIR KNOWLEDGE AND EXPECTATIONS OF ADJUVANT THERAPY. This article explains how improvements in doctor and patient communication may be important to informed decision-making in breast cancer treatment and that consideration of individual patients’ preferences need not be superseded by rigid treatment guidelines. Ravdin, P. M., Siminoff, I. A. & Harvey, J. A. (1998). *Journal of Clinical Oncology*, 16 (2), 515 – 521.

PATIENT-PROVIDER AGREEMENT ON GUIDELINES FOR PREPARATION FOR BREAST CANCER TREATMENT. When guidelines for preparing patients for breast cancer treatment were developed patients and nurses rated the guidelines as important aspects of good quality care. Items which patients viewed as important included: consistency of information, involvement of others in preparation, and assistance to the patient in coping with treatment for breast cancer. Schofield, M. J., Walkom, S. & Sanson-Fisher, R. (1997). *Behavioral Medicine*, 23 (1), 36 – 45.

THE IMPACT OF AGE, MARITAL STATUS, AND PHYSICIAN-PATIENT INTERACTIONS ON THE CARE OF OLDER WOMEN WITH BREAST CARCINOMA. The authors recommend when older women are newly diagnosed with breast cancer and there is clinical uncertainty as to the most appropriate therapies, patients might be better served if they are offered choices from among definitive therapies. In discussing therapies patients preferred physicians who were sensitive to their fears and concerns about the monetary costs and functional consequences of treatment in relation to the expected benefits. Silliman, R. A., Troyan, S. L., Guadagnoli, E., Kaplan, S. H. & Greenfield, S. (1997) *Cancer*, 80 (7), 1326 – 1334.

Communicating Breast Cancer Risk

Women concerned about their risk for breast cancer want and need accurate information regarding the possibility of developing the disease. How can patients and physicians work together to appropriately assess risk?


THE SPECIAL SURVEILLANCE BREAST PROGRAM: A MODEL OF INTERVENTION FOR WOMEN AT HIGH RISK FOR BREAST CANCER. The Special Surveillance Breast Program is for women determined to be at high risk for the development of breast cancer. This article describes the risk factors that indicate eligibility for the program, the program’s structure, and the results of an assessment that identified the needs of this special population. Gross, R. E., Van Zee, K. J. & Heerdt, A. S. (1997). Journal of the New York State Nurses Association, 28 (4), 9 – 12.

PUTTING THE RISK OF BREAST CANCER IN PERSPECTIVE. Several studies have shown that women tend to overestimate their risk of breast cancer and that many fail to understand the importance of age as a risk factor. This editorial details the importance of describing information about breast cancer risk in context. Phillips, K. A., Glendon, G. & Knight, J. A. (1999). New England Journal of Medicine, 340 (2) 141 – 144.

Tools for Use by Patients

Better understanding of the risks of breast cancer onset, treatment, and outcomes can be facilitated with patient education tools. This section presents ways that information can be given to patients to share with their family members and caregivers while making treatment decisions. Tools available include fact sheets, graphic displays, information booklets, and interactive computer programs.

AN EDUCATION PROGRAM FOR FAMILIES. This is a letter written to a column on practical nursing tips. The authors identify educational methods and opportunities for teaching about cancer. Highlighting information that can be used in screening, patient support, and support of family members, this piece discusses both ongoing programs and individual resources. Facciponti, C. A. & Cartwright, F. (1989). Oncology Nursing Forum, 16 (3), 432.

INTERACTIVE VIDEO ASSISTS IN CLINICAL DECISION MAKING. The authors describe a project to implement and evaluate interactive videodisk programs. The programs are intended to assist in clinical decision-making for breast cancer by providing patients with information about available treatment options. Gramlich, E. P. & Waitzfelder, B. E. (1998). *Methods of Information in Medicine, 37*(2), 201 – 205.

A BEDSIDE DECISION INSTRUMENT TO ELICIT A PATIENT’S PREFERENCE CONCERNING ADJUVANT CHEMOTHERAPY FOR BREAST CANCER. This study developed an instrument to help clinicians inform patients about risks and benefits of adjuvant chemotherapy. The instrument, called a decision board, is used to explain probable outcomes of therapy choices and to help the informed patient decide what, if any, treatment is preferred. Levine, M. N., Gafni, A., Markham, B. & MacFarlane, D. (1992). *Annals of Internal Medicine, 117*, 53 – 58.

BREAST CANCER TREATMENT GUIDELINES FOR PATIENTS. This booklet is a joint publication of the National Comprehensive Cancer Network (NCCN) and the American Cancer Society. Its goal is to provide patients and the general public with state-of-the-art cancer treatment information in understandable language. Based on the NCCN treatment guidelines, this document contains information on cancer types, staging, diagnosis, and treatment. The National Comprehensive Cancer Network and the American Cancer Society. (1999). (Available from the American Cancer Society, 1599 Clifton Road N. E., Atlanta, GA 30329). [On-line]. Available: [http://www.nccn.org/patient_guidelines/Breast/Page1.htm](http://www.nccn.org/patient_guidelines/Breast/Page1.htm)


Treatment Planning

Patient’s needs have long been elicited through the use of patient satisfaction surveys, which frequently are not designed to obtain the in-depth information needed to guide the improvement of health care services. These articles describe other ways to assess patient information needs as well as strategies for information dissemination.

ASSESSING THE NEEDS OF BREAST CANCER PATIENTS AND THEIR FAMILIES. The authors developed and conducted a needs assessment survey for women with breast cancer. This article outlines this process and the results, which were used to create a computer program to help women with breast cancer. Gustafson, D. H., Taylor, J. O., Thompson, S. & Chesney, P. (1993). Quality Management in Health Care, 2 (1), 6 – 17.

INFORMATION NEEDS OF FAMILIES OF CANCER PATIENTS: A LITERATURE REVIEW AND RECOMMENDATIONS. This paper analyzes the kinds of information family members of cancer patients find helpful, discusses why families frequently may not receive information, and suggests strategies for meeting their information needs. Strategies include wider distribution of generic information about cancer and treatments to family members and developing standard professional procedures to make information about a patient’s clinical condition available to them. Houts, P. S., Rusenas, I., Simmonds, M. A. & Hufford, D. L. (1991). Journal of Cancer Education, 6 (4), 255 – 261.

PHYSICIAN AND PRACTICE CHARACTERISTICS ASSOCIATED WITH JUDGMENTS ABOUT BREAST CANCER TREATMENT. This study found that practices of surgeons and physicians who participated in information networks focused on cancer, and those with more breast cancer patients, were more consistent with the National Institute of Health Consensus Conferences on breast cancer. It states that concurrence with Consensus Conference positions was less likely in older physicians and those in solo practice. McFall, S. L., Warnecke, R. B., Kaluzny, A. D., Aitken, M. & Ford, L. (1994). Medical Care, 32 (2), 106 – 117.

INTERNET AND WEB RESOURCES

Overview

The proliferation of Internet use and health related information on the Internet can be both exciting and overwhelming. These articles explain how health care professionals, patients, and families can begin to find, assess, and use the information that is available. An extensive breast cancer Web site archive is included in Appendix A of this document.

BREAST CANCER RESOURCES ONLINE. The rapid growth of Internet resources on breast cancer is helping to fill the information gap that those with the disease often faced in the past. This article provides an overview of breast cancer Web sites and the advantages and disadvantages of Internet use. Haines. J. (1997). Canadian Nurse, 93 (9), 49 – 50.

Assessing Quality of Information on the Internet

The demand for health information is reflected in the fact that there are currently over 10,000 health-related Web sites. A recent report states that 36.7% of the general Internet user population accesses the Web to retrieve health and medical information. The quality of online medical and health information continues to be controversial. These articles provide an overview of quality criteria for these Web sites.


ASSESSING THE QUALITY OF ONLINE MEDICAL INFORMATION. Quality of on-line medical information is important, but no single source is able to definitively identify quality standards. This recent search for on-line resources for quality assessment identifies new resources worth checking. (1998). Internet Medicine, 3 (11), 1, 5, 6. [On-line]. Available: http://news.medscape.com/LWW/IM/1998/v03.n11/im0311.01.html


On-Line Communications with Patients

Breast cancer patients may find that the Internet is a good source of informational and emotional support. The resources available on the Internet can be accessed at the patient’s convenience and in varying formats. Understanding how and why patients use the Internet can give insight into their psychosocial and informational needs.

COMMUNICATING BREAST CANCER ON-LINE: SUPPORT AND EMPOWERMENT ON THE INTERNET. This article explores the communication occurring in a breast cancer on-line discussion group. Three major dimensions of user involvement were identified: exchange of information, social support, and personal empowerment. The author found that the group fulfills the functions of a community, and stated concerns about information control and the potential to enhance patient-provider understanding. Sharf, B. F. (1997). Women and Health, 26 (1), 65 – 84.
New York State

CONSUMERS’ BREAST AND CERVICAL CANCER SERVICES – NEW YORK STATE DEPARTMENT OF HEALTH. The New York State Department of Health site presents the state standards for mammography facilities and lists facilities by service area. Information about breast cancer studies and instructions for breast self-exam is also included. Available: http://www.health.state.ny.us/nysdoh/consumer/cancer/cancer2.htm


BREAST CANCER AND ENVIRONMENTAL RISK FACTORS IN NEW YORK STATE. This Cornell University resource contains maps of breast cancer incidence and mortality by county in New York State. It also provides information on the relationships between breast cancer and environmental risk factors, including pesticides and dietary factors. Available: http://www.cfe.cornell.edu/bcerf/

Federal Government

CENTER FOR DISEASE CONTROL’S ORDER LINK FOR BREAST CANCER PUBLICATIONS. This site is the Center for Disease Control’s Internet order form for and links to breast cancer publications regarding strategies, guidelines, and more. Available: http://www.cdc.gov/nccdphp/dcpc/publica.htm#breast

NATIONAL CANCER INSTITUTE’S CANCERNET. CancerNet contains a range of cancer information including summaries on cancer treatment, screening, prevention, and supportive care. Information on ongoing clinical trials, a bibliographic database, fact sheets, news, and other resources are also provided. Available: http://cancernet.nci.nih.gov/

OFFICE OF MINORITY HEALTH RESOURCE CENTER. This site includes minority information on breast cancer including fact sheets, toll-free phone numbers, breast health resources, and links to other organizations. “A Breast Cancer Resource Guide for Minority Women” can be downloaded at the Publications link. Available: http://www.omhrc.gov/frames.htm

National Organizations

AMERICAN CANCER SOCIETY. This site is the American Cancer Society’s on-line resource for breast cancer information and programs including research, survivorship, and advocacy. “Breast Cancer Treatment Guidelines for Patients” produced collaboratively by the Society and the National Comprehensive Cancer Network is also available here. Available: http://www2.cancer.org/ncn/index.html
NATIONAL ALLIANCE OF BREAST CANCER ORGANIZATIONS (NABCO). NABCO’s site provides information regarding breast cancer resources, support groups, clinical trials and more. Selections from 1997/98 edition of the NABCO Breast Cancer Resource List are available as well as information about breast cancer legislative and regulatory concerns. Available: http://www.nabco.org/

NATIONAL COALITION FOR CANCER SURVIVORSHIP (NCCS). This NCCS site is for cancer survivors of all ages, friends and loved ones, healthcare providers, professional organizations and agencies, and research and medical centers. Information is presented about a variety of survivorship programs. CanSearch assists on-line users in finding Internet cancer resources. The Web site is available in English and Spanish. Available: http://www.cansearch.org/

ONCOLOGY NURSING SOCIETY. The Oncology Nursing Society’s interactive site contains resources for patient care, teaching, research, administration, and education in oncology. On-line discussion groups and an on-line library can also be found here. Available: http://www.ons.org/

Y-ME NATIONAL BREAST CANCER ORGANIZATION. The Y-ME site is designed to be a support and information resource for anyone who has been affected by breast cancer. It has phone numbers for the Y-ME National Breast Cancer Hotline (in English and Spanish) and an archive of Internet resources. The Web site is available in English and Spanish. Available: http://www.y-me.org/

Breast Cancer Information Sites


BREAST CANCER AWARENESS AND SOLUTIONS NETWORK (BCASN). Developed by the Department of Defense, the BCASN site is intended to increase awareness about breast cancer issues for healthcare providers, breast cancer patients and their families, and the general public. It contains downloadable patient education brochures, a library of on-line research articles and more. Available: http://216.104.144.179/content/default.asp

BREAST CANCER WEB: SURVIVORS GATEWAY TO THE INTERNET. The Breast Cancer Web presents products, services, and information for breast cancer survivors. It has an appendix of medicines used to treat breast cancer or to decrease side effects of treatment. A link page covers all aspects of the breast cancer experience. Available: http://www.chsvc.com/

BREASTCANCER.NET. The BreastCancer.Net site has news regarding breast cancer detection and treatment and provides a free E-mail news service. Available: http://www.breastcancer.net/
INTERACTIVE SITE ON BREAST CANCER AWARENESS. The Interactive Site is a patient decision support system that provides a multimedia package of information promoting early detection and treatment of breast cancer. The site is designed for women, their family members, and physicians. The Department of Defense developed this site.

INTELIHEALTH - JOHNS HOPKINS BREAST CANCER INFORMATION. InteliHealth contains breast cancer information, news on treatment and research, and a message posting board.

MEDSCAPE’S WOMEN’S HEALTH PAGE. Medscape provides clinical information applicable to patients and best practice, organized as a set of file folders for rapid review and retrieval. Resources include practice guidelines, a library with a breast cancer journal scan, and a multi-database search engine.

ONCOLINK BREAST CANCER: GENERAL INFORMATION. The University of Pennsylvania’s Oncolink Breast Cancer site provides information on aspects of breast health, cancer treatment and survivor issues. It is linked directly to the National Cancer Institute’s CANCERLIT database. The Breast Cancer Risk Assessment Tool is a free download from this site.
Available: http://oncolink.upenn.edu/disease/breast/

SUSAN G. KOMEN BREAST CANCER FOUNDATION. This site has message posting boards and a National Toll-Free Breast Care Helpline. Grant and funding opportunities are described and downloadable grant applications are available. Breast health and cancer information can be accessed through a direct link to breastcancerinfo.com, an informational service of the Komen Foundation.
Available: http://www.komen.org/

Survivorship/Support Groups

ADELPHI UNIVERSITY NEW YORK STATEWIDE BREAST CANCER SUPPORT HOTLINE. This Adelphi University site has information regarding Adelphi’s Statewide Toll-Free Breast Cancer Hotline. Information is available about free written materials from many sources including the National Cancer Institute and the American Cancer Society, as well as Adelphi’s own material.
Available: http://icculus.adelphi.edu/bcancer/

SHARE – SELF-HELP FOR WOMEN WITH BREAST CANCER. SHARE’s services include information hotlines in English and Spanish and materials about peer-led support groups, public education, advocacy and wellness programs. The Web site is available in English and Spanish.
Available: http://www.sharecancersupport.org/
Research Journals

**JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION.** This JAMA site includes issues from 1995 to the present with articles in abstract form. A Women’s Health Information Center may also be accessed here.

**JOURNAL OF CLINICAL ONCOLOGY.** This Journal of Clinical Oncology site includes issues from 1996 to the present with articles in abstract form.

**THE NEW ENGLAND JOURNAL OF MEDICINE.** This NEJM site includes issues from 1993 to the present with articles in abstract form. Subscribers can access a NEJM Breast Cancer Collection and subscribe to a free on-line newsletter.
Available: [http://www.nejm.org/content/index.asp](http://www.nejm.org/content/index.asp)

Clinical Practice Guidelines/Best Practices

**Agency for Health Care Policy and Research (AHCPR).** The AHCPR site contains Clinical Practice Guidelines, Quick Reference Guides for Physicians, and Consumer’s Guides for Quality Mammography and Management of Cancer Pain (in English and Spanish) among others. All publications are downloadable.

**AMERICAN SOCIETY FOR CLINICAL ONCOLOGY (ASCO).** The ASCO site contains recommended Breast Cancer Surveillance Guidelines and Clinical Practice Guidelines for Use of Tumor Markers in Breast Cancer among others. All publications may be printed from the Web.

**BEST PRACTICE NETWORK.** The Best Practice Network has a variety of resources that focus on best practice development and implementation. Many articles, presentations, and interviews are downloadable.

**INSTITUTE FOR HEALTH CARE IMPROVEMENT (IHI).** The IHI site has resources to help health care professionals lead and manage improvement efforts at their organizations. Access improvement guides, Quality Connection Newsletter (subscribe for free), web links and more.

**NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN).** This NCCN site has Breast Cancer Practice Guidelines and new Breast Cancer Screening Practice Guidelines. “Breast Cancer Treatment Guidelines for Patients” produced collaboratively by NCCN and the American Cancer Society is also available here.
Available: [http://www.cancernetwork.com/indexes/nccn.htm](http://www.cancernetwork.com/indexes/nccn.htm)

**THE PICKER INSTITUTE.** The Picker Institute site contains health care quality assessment and improvement strategies that address needs and concerns as defined by patients. Patient satisfaction surveys, educational programs and resources are described.
Healthcare Organizations/Institutes

AMERICAN COLLEGE OF SURGEONS. The American College of Surgeons site has information on patient choice and decision-making about surgery and on-line ordering of cancer publications. It also provides access to information and data pertinent to initiating a cancer registry program. Available: http://www.facs.org/

AMERICAN COLLEGE OF RADIOLOGY. The American College of Radiology site has samples of lay reports for direct reporting of results to women by mammography facilities. It also has downloadable criteria for breast radiation oncology. Available: http://www.acr.org/

CENTERWATCH CLINICAL TRIALS LISTING SERVICE. CenterWatch has patient resources including a list of new FDA drug therapy approvals, listings, and explanations about clinical trials, and a listing of National Institute of Health studies. Visitors may request E-mail notification of future clinical trials and FDA drug approval in particular clinical areas. Available: http://www.centerwatch.com/

Breast Cancer Link/Search Sites

ASSOCIATION OF CANCER ON-LINE RESOURCES, INC. (ACOR). The ACOR site offers 69 on-line cancer information and support electronic groups, providing support to patients, caregivers, or anyone looking for answers and support about cancer and related disorders. Available: http://www.acor.org/

BEST WEB SITES ON BREAST CANCER VERSION 1.8. Best Web Sites is a list of sites with information on breast cancer. It is designed to assist with research regarding treatment options for breast cancer. Available: http://darkwing.uoregon.edu/~jbonine/bc_sources.html

CANCERGUIDE. CancerGuide is designed to help consumers find the answers to questions about cancer. It presents information on specific cancers, researching the medical literature, clinical trials, and more. Available: http://www.cancerguide.org/


NCI HEALTHFINDER LINKS PAGE. Healthfinder contains links to breast cancer on-line publications, clearinghouses, databases, web sites, self-help groups, and the government agencies and not-for-profit organizations that produce information for the public. Available: http://www.healthfinder.gov/tours/brcancer.htm
SCREENING AND PREVENTION

Screening and Surveillance Guidelines


1997 UPDATE OF RECOMMENDATIONS FOR THE USE OF TUMOR MARKERS IN BREAST AND COLORECTAL CANCER. The primary objective of these recommendations was to update the 1996 clinical practice guidelines for the use of tumor marker tests in the prevention, screening, treatment, and surveillance of breast and colorectal cancers. These guidelines are intended for use in the care of patients outside of clinical trials. American Society of Clinical Oncology. (1998). Journal of Clinical Oncology, 16 (2), 793 – 795.

Screening Programs

Timely and appropriate screening programs include effective outreach, convenient services, and comprehensive follow-up. Changing views of breast cancer and mammography over time have made screening more acceptable, but some patients still do not adhere to screening guidelines. The articles in this section address particular social, economic, racial or cultural issues that either encourage or deter women from participating in mammography.


THE NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM: AT-A-GLANCE 1998. This publication describes the Center for Disease Control’s breast and cervical cancer early detection program, which includes New York State. The program brings critical breast and cervical cancer screening to under-served women, including older women, women with low income, and women of racial and ethnic minority groups. Screening and follow-up services, public education and outreach, and partnership and coalition development are described. Center for Disease Control and Prevention. (1998). (Available from the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Mailstop K-64, 4770 Buford Highway, NE, Atlanta, GA 30341-3724) [On-line]. Available: http://www.cdc.gov/nccdphp/dcpc/nbccedp/about.htm
REACHING WOMEN FOR MAMMOGRAPHY SCREENING. The purposes of this guide are to provide background and explain infrastructure to: identify potential strategies to increase mammography screening rates in selected populations, and develop collaborations (especially between public sector organizations and managed care organizations) to implement these strategies. Center for Disease Control and Prevention. (1997). (Available from the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Mailstop K-64, 4770 Buford Highway, NE, Atlanta, GA 30341-3724) [On-line]. Available: http://www.cdc.gov/nccdphp/dcpc/publica.htm#breast

A COMPARISON OF SCREENING MAMMOGRAPHY RESULTS FROM PROGRAMS FOR WOMEN OF DIFFERENT SOCIOECONOMIC STATUS. This article compares the rate of screening mammography programs serving women of lower SES to those of more socio-economically advantaged women. The authors conclude that screening programs can be equally efficient and effective for both socio-economic groups. Dershaw, D. D., Loring, L., True, S. J., Momrow, D. C., Liberman, L., Morris, E. A. (1998). Cancer, 82 (9), 1692 – 1697.

CHRONIC DISEASE AS A BARRIER TO BREAST AND CERVICAL CANCER SCREENING. The objective of this study was to assess whether chronic disease is a barrier to screening for breast and cervical cancer. The authors found that among women who sought outpatient care, screening rates decreased as comorbidity increased. Kiefe, C. I., Funkhouser, E., Fouad, M. N. & May, D. S. (1998). Journal of General Internal Medicine, 13 (6), 357 – 365.

STRATEGIES TO ENCOURAGE MAMMOGRAPHY USE AMONG WOMEN IN SENIOR CITIZENS’ HOUSING FACILITIES. This randomized trial evaluated the impact of mammography-enhancing interventions implemented in senior citizens’ housing facilities. The results suggest that the combination of community-directed mammography education and access to mammography appointments encourage mammography use primarily by women who are already predisposed to screening. King, E., Rimer, B. K., Benincasa, T., Harrop, C., Amfoh, K., Bonney, G., Kornguth, P., Demark-Wahnefried, W., Strigo, T. & Engstrom, P. (1998). Journal of Cancer Education, 13 (2), 108 – 115.

FACTORS ASSOCIATED WITH WOMEN’S ADHERENCE TO MAMMOGRAPHY SCREENING GUIDELINES. This study found that the following patient and system characteristics positively influenced mammography adherence: younger patient age, smaller families, higher education and income, recent Pap smear, self-reported breast problems, residence in an area with a higher percentage of mammography facilities, no shortage of primary care providers, higher HMO market share, and higher screening charges. The authors state that since only a small percentage of women adhere to screening guidelines, adherence needs to become a focus of clinical, programmatic, and policy efforts. Phillips, K. A., Kerlikowske, K., Baker, L. C., Chang, S. W. & Brown, M. L. (1998). Health Services Research, 33 (1), 29 – 53.

CANCER SCREENING IN THE POSTMENOPAUSAL WOMAN. This is an overview article, giving brief, statistical, prognostic and screening information for all major forms of cancer common to older women. The author describes both the prevalence and mortality rates for each type of cancer and makes recommendations for screening type and frequency. Seltzer, V. (1996). Clinical and Obstetrical Gynecology, 39 (4), 889 – 892.
COMMUNITY-BASED BREAST HEALTH PARTNERSHIPS. This article describes New York State’s Breast Health Partnership, a community-based program delivering breast cancer screening services to women in all 62 counties in the state. The partners include representatives from government agencies as well as the voluntary and private sectors who utilize their resources to overcome obstacles to the delivery of breast cancer screening services to under-served, uninsured, or poorly insured women. True, S. J. (1995). *Journal of Public Health Management Practice*, 1 (3), 67 –72.

THE MANUAL OF INTERVENTION STRATEGIES TO INCREASE MAMMOGRAPHY RATES. This manual provides information on mammography and the intervention strategies and tools that health plans may use to increase screening rates. It is designed to assist health plans to assess barriers, identify target populations, select and implement appropriate intervention strategies, and monitor and evaluate intervention strategies to further improve screening rates. Wong, F. L. (1997). (Available from the National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control, Mailstop K-64, 4770 Buford Highway, NE, Atlanta, GA 30341-3724) [On-line]. Available: http://www.cdc.gov/nccdphp/dcpc/nbccedp/bccpdfs/prumanual.pdf

**Newsletters and Other Information Resources**

*The following materials provide an overview of breast cancer resources and examples of consumer focused material. Numerous publications exist in addition to those listed below; one of the most actively used resources is the Internet. See also: Internet and Web Resources.*

**BREAST CANCER RESOURCE LIST.** This list is a guide to resources about breast cancer. Topic areas include prevention and treatment, survivorship, sources of medical information and support, and materials and educational resources for health professionals. Sources for frequently cited resources are listed as well as additional sources of help. *National Alliance of Breast Cancer Organizations.* (1997). New York: Author.


**PRIMARY CARE AND BREAST CANCER**

*Primary care physicians are the main source of referral for breast cancer screening. Researchers recommend that primary care providers have a strong understanding of the causes and forms of breast cancer and recommended diagnostic and treatment follow-up protocols.*

**EVALUATION OF COMMON BREAST PROBLEMS: GUIDANCE FOR PRIMARY CARE PROVIDERS.** This article presents the Commission on Cancer of the American College of Surgeons and the Society of Surgical Oncology’s guidelines for primary care providers to

A COMPARISON OF SCREENING MAMMOGRAPHY RESULTS FROM PROGRAMS FOR WOMEN OF DIFFERENT SOCIOECONOMIC STATUS. This article examines the ability of screening mammography programs serving women of different socioeconomic status to diagnose early stage breast carcinoma in a comparably effective manner. The authors found that screening mammography programs can be effective for women of lower SES and can be conducted as efficiently as they are for more affluent women. Dershaw, D. D., Loring, L., True, S. J., Momrow, D. C., Liberman, L. & Morris, E. A. (1998). Cancer, 82 (9), 1692 – 1697.


OBSTETRICS AND GYNECOLOGY RESIDENCIES: EDUCATION IN PREVENTIVE AND PRIMARY HEALTH CARE FOR WOMEN. This study tested the hypothesis that the Residency Review Committee program requirements for obstetrics and gynecology residencies, when properly followed, will result in residents being educated in preventive and primary ambulatory health care for women during their residency training program as specialists in obstetrics and gynecology. It found that physicians in the residency training program in obstetrics and gynecology were being educated to provide preventive and ambulatory primary health care for women. Seltzer, V. L., Fishburne, Jr., J. I. & Jonas, H. S. (1998). Obstetrical Gynecology, 91 (2), 305 – 310.

Risk Factors

Breast cancer risk assessment is a subject of current debate. Consumers can readily access the popular media for breast cancer information on such topics as epidemiology and environmental research. Providers may improve communications with patients by understanding the availability and contents of this information. See also: Communicating Breast Cancer Risk and Patient Preferences in Communications.

THE EPIDEMIOLOGIC CHARACTERISTICS OF BREAST CANCER. The author provides a survey of the epidemiological characteristics of breast cancer including: personal and environmental risk factors for breast cancer, established risk factors for breast cancer in females, and factors that do not appear to influence cancer development. The article states


Prevention Methods

Although recent breast cancer studies identify numerous risk factors that may influence the development of the disease, the vast majority of breast cancers diagnosed have no known risk factors. The articles in this section investigate factors that may decrease or inhibit potential breast cancer growth. Articles on chemoprevention methods, nutritional supplements, and genetic screening are also included.

CURRENT METHODS TO PREVENT THE DEVELOPMENT OF BREAST CANCER.

Women at high risk for breast cancer are most likely to benefit from chemoprevention, but have traditionally been difficult to identify. The identification of the BRCA1 and BRCA2 breast cancer susceptibility genes have provided the opportunity for identification of high risk women. This article describes the development of and steps involved in effective chemoprevention strategies. Cristofanilli, M. & Hortobagyi, G. N. (1998). In Vivo, 12 (6), 659 – 666.

NUTRITION AND BREAST CANCER. A variety of current information links nutrition and dietary factors to the risk of developing breast cancer, as well as to survival and outcomes after a diagnosis of breast cancer. Epidemiologic and other data suggest that high-fat and low-fiber diets are associated with an increased risk of breast cancer. Several pilot studies have been performed to decrease dietary fat intake in women with breast cancer. Other studies suggest that weight gain after breast cancer is common and may be detrimental to survival. Ganz, P. A. & Schag, A. C. (1993). Oncology, 7 (12), 71 – 75; discussion 76, 79 – 80.


GENETIC TESTING FOR BRCA1 AND BRCA2: RECOMMENDATIONS OF THE STANFORD PROGRAM IN GENOMICS, ETHICS, AND SOCIETY. BREAST CANCER WORKING GROUP. Genetic testing for mutations in BRCA1 and BRCA2, which are associated with increased lifetime risk of breast and ovarian cancer, may become the first widely accessible genetic testing for common adult onset diseases. The authors state that testing for

**Prophylactic Mastectomy**

Prophylactic mastectomy is the most invasive form of preventive treatment that women can undergo. Some research indicates that prophylactic mastectomy may be associated with a reduction in the incidence of breast cancer for women who anticipate breast disease.

Additional research indicates that the majority of the women who undergo this surgery may not have developed breast cancer, and that genetic screening as an indicator of risk may lead to unnecessary surgeries.

**PROPHYLACTIC MASTECTOMY-THE PRICE OF FEAR.** The authors provide a review of the study by Hartmann and colleagues that appears in the same issue of the journal (see below). They point out that in the study of 639 women, instead of the 20 deaths related to breast cancer that were expected during the period of observation, there were only two. They state that the saving of those 18 lives is clearly important, but the 621 women probably would have survived without prophylactic mastectomy. Eisen, A. & Weber B. L. (1999). New England Journal of Medicine, 340 (2) 137 – 138.

**EFFICACY OF BILATERAL PROPHYLACTIC MASTECTOMY IN WOMEN WITH A FAMILY HISTORY OF BREAST CANCER.** This is a retrospective study of all women with a family history of breast cancer who underwent bilateral prophylactic mastectomy at the Mayo Clinic between 1960 and 1993. The authors found that in women with a high risk of breast cancer on the basis of family history, prophylactic mastectomy can significantly reduce the incidence of breast cancer. Hartmann, L. C., Schaid, D. J., Woods, J. E., Crotty, T. P., Myers, J. L., Arnold, P. G., Petty, P. M., Sellers, T. A., Johnson, J. L., McDonnell, S. K., Frost, M. H. & Jenkins, R. B. (1999). New England Journal of Medicine, 340 (2) 77 – 84.

**STUDY SHOWS MASTECTOMY PREVENTS BREAST CANCER IN HIGH-RISK WOMEN.** The availability of genetic testing raises the question: how can this knowledge be useful to women? The article examines the evidence indicating that prophylactic mastectomy in women at high risk for breast cancer dramatically reduces their chances of developing the disease. Stephenson, J. (1997). Journal of the American Medical Association, 277 (18), 1421 – 1422.
**Guidelines for Mammography**

*Mammography is one of the least invasive and most effective forms of breast cancer screening. It allows physicians to detect cancerous masses far earlier than most tactile forms of screening. Controversy does exist, however, around the optimal ages for mammography use. The articles listed are a sampling of the clinical guidelines available for mammography.*

**QUALITY DETERMINANTS OF MAMMOGRAPHY – CLINICAL PRACTICE GUIDELINE NUMBER 13.** A multidisciplinary panel of clinicians developed this guideline with support from the Agency for Health Care Policy and Research. There are many links in the chain of events that comprise mammography. The panel’s task was to consider each of these links, identify where problems exist, and define a guideline to ensure quality and eliminate identified problems. *Agency for Health Care Policy and Research. (1994, October).* [On-line]. Available: [http://text.nlm.nih.gov/](http://text.nlm.nih.gov/)

**RISK-BASED RECOMMENDATIONS FOR MAMMOGRAPHIC SCREENING FOR WOMEN IN THEIR FORTIES.** This study developed risk-based recommendations for mammography screening for women in their 40s that take into account the woman’s age, race, and specific risk factors. For women or physicians who prefer an individualized approach in deciding whether to initiate regular mammography screening in the 40 through 49 years age range, this report offers recommendations based on individualized risk-factor data. *Gail, M. & Rimer, B. (1998). Journal of Clinical Oncology, 16 (9), 3105 – 3114.*


**NATIONAL INSTITUTES OF HEALTH CONSENSUS DEVELOPMENT CONFERENCE STATEMENT: BREAST CANCER SCREENING FOR WOMEN AGES 40-49.** This is an assessment of currently available data regarding the effectiveness of mammography screening for women ages 40 through 49. It states that the data currently available do not warrant a universal recommendation for mammography for all women in their forties. *National Institutes of Health Consensus Development Panel. (1997). Journal of the National Cancer Institute, 89 (14), 1015 – 1026.*

**A SCIENCE FOR THE ART OF CONSENSUS.** This article examines the National Institutes of Health Consensus Development Conference’s majority and minority opinions on screening mammography for women ages 40 through 49. The National Cancer Advisory Board later recommended screening women in their forties. Public reaction was polarized in the ensuing confusion. *Sackett, D. L. (1997). Journal of the National Cancer Institute, 89 (14), 1003 – 1005.*
Mobile Mammography

Mobile mammography vans can make breast cancer screening more accessible to women at health fairs, in neighborhoods, and in the workplace. Mobile mammography is one way that cancer service providers can invest in diagnostic equipment to provide outreach services to a larger population.

OUTCOMES OF RECOMMENDATIONS FOR BREAST BIOPSIES IN WOMEN RECEIVING MAMMOGRAMS FROM A COUNTY HEALTH VAN. This article describes the outcomes of breast biopsy recommendations for women screened through a mobile mammography van. It found that a breast cancer screening program using a mobile van could have comparable cancer detection rates to national figures and a fairly stable biopsy recommendation rate from which follow-up resource needs could be estimated. Kann, P. E., Bradley, C. & Lane, D. S. (1998). Public Health Reports, 113 (1), 71 – 74.


BREAST CANCER DIAGNOSIS AND TREATMENT

This literature review does not recommend diagnostic or treatment protocols or attempt to give an exhaustive review of the literature. Innovations in the clinical treatment of breast cancer are based on scientific inquiry and clinical testing, both of which are beyond the scope of this project. The articles included highlight published clinical guidelines as well as recent developments that have received significant press.

Breast Cancer Treatment Overview

These articles provide introductions to the diagnosis and surgical treatment of cancer. They may be useful for patient navigation and other staff who are interested in introductory information.


INVESTIGATION OF LESIONS DETECTED BY MAMMOGRAPHY. This study presents information and recommendations for facilitating decision-making when a mammographic abnormality is detected by screening. Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. (1998). Canadian Medical Association Journal, 158 (Suppl. 3), 9 – 14.

AN OVERVIEW OF SURGICAL MANAGEMENT OF STAGE I AND STAGE II BREAST CANCER FOR THE PRIMARY CARE PROVIDER. This article furnishes the Primary Care Provider (PCP) with a guide to the surgical management of breast cancer, focusing on preoperative evaluation, common surgical treatments for early breast cancer, risks and complications of surgical treatment and breast reconstruction, educational topics, and psychological support issues. The information presented allows the PCP to provide essential interventions in collaboration with the breast specialist from the diagnosis of breast cancer through the postoperative period. Strozzo, M. D. (1998). Lippincott’s Primary Care Practice, 2 (2), 160 – 169.

Surgical Approaches

In October 1998, the Federal Women’s Health and Cancer Rights Act guaranteed insurance coverage for inpatient care following a mastectomy, lumpectomy, or lymph node dissection. It also provides for coverage for reconstructive procedures. Sites participating in a Breast Cancer Demonstration Project Fall 1998 survey at their hospitals reported lumpectomy with reconstruction are the surgeries most often performed.

Clinical Practice Guidelines on Breast Surgery

BREAST CANCER SURGICAL PRACTICE GUIDELINES. The Society of Surgical Oncology surgical practice guidelines focus on the signs and symptoms of primary cancer, timely evaluation of the symptomatic patient, appropriate preoperative evaluation for the extent of disease, and role of the surgeon in diagnosis and treatment. Following each guideline is a brief narrative highlighting and expanding on selected sections of the guideline document with a few relevant references. Morrow, M., Bland, K. I. & Foster, R. (1997). Oncology, 11 (6), 877 – 886.

Sentinel Node Biopsy


Reconstruction

BREAST RECONSTRUCTION FOLLOWING MASTECTOMY. Modern breast reconstruction techniques can provide breast cancer patients a source of rehabilitation and an alternative to breast loss. This article describes how with a surgical oncologist and plastic surgeon working together, mastectomy and breast reconstruction may be combined in one operation with less skin removal, shorter scars, and reduced inconvenience for the patient. Bostwick, J. (1995). CA – A Cancer Journal for Clinicians, 45 (5), 289 – 304.

Chemotherapies

Innovations and adaptations of adjuvant chemotherapies change rapidly. The potential uses, risks and implications of the new drugs herceptin, xeloda, and tamoxifen have received significant press. The following articles highlight the types of therapies studied and the construct of the studies themselves.

LONG-TERM PAMIDRONATE TREATMENT OF ADVANCED MULTIPLE MYELOMA PATIENTS REDUCES SKELETAL EVENTS. The purpose of this study was to determine the efficacy and safety of 21 monthly cycles of Pamidronate therapy in patients with advanced multiple myeloma. The study found that Pamidronate was safe and well tolerated during the 21 cycles of therapy. Berenson, J. R., Lichtenstein, A., Porter, L., Dimopoulos, M. A., Bordoni, R., George, S., Lipton, A., Keller, A., Ballester, O., Kovacs, M., Blacklock, H., Bell, R., Simeone, J. F., Reitsma, D. J., Heffernan, M., Seaman, J. & Knight, R. D. (1998). Journal of Clinical Oncology, 16 (2), 593 – 602.

PRIMARY CHEMOTHERAPY IN OPERABLE BREAST CANCER: EIGHT-YEAR EXPERIENCE AT THE MILAN CANCER INSTITUTE. In this study primary chemotherapy was administered to patients with tumors that measured 2.5 cm or larger to decrease the size of the primary tumor and allow for effective local and distant control while avoiding mastectomy. Its findings indicate that primary chemotherapy can safely be administered in women with large tumors (larger than 5.0 cm) and can allow breast-sparing surgery in a high percentage of patients (62%). Bonadonna, G., Valagussa, P., Brambilla, C., Ferrari, L., Moliterni, A., Terenziani, M. & Zambetti, M. (1998). Journal of Clinical Oncology, 16 (1), 93 – 100.


Radiation Therapy

This overview article on radiation therapy is useful for its communications strategies. Radiation is still largely at the discretion of the radiation oncologist who evaluates the therapy in terms of its therapeutic and palliative qualities.

RADIATION THERAPY FOR PRIMARY BREAST DISEASE. This article addresses factors that may be considered in counseling a breast cancer patient to select the appropriate local regional treatment. It also describes indications for local regional radiation after mastectomy (including those of patients in autologous bone marrow transplant programs), the sequencing of postsurgery radiation, and any needed chemotherapy therapy, and radiation doses and techniques. McCormack, B. (1994). Clinical Obstetrics and Gynecology, 37 (4), 967 – 977.

Clinical Trials and Research

Clinical trials are the primary way new cancer prevention methods and treatments can be refined. They present cancer researchers with a number of costly and labor intensive hurdles including identifying participants and maintaining testing databases. Until recently, HMOs did not endorse clinical trials and many insurers, HCFA included, did not reimburse for them. These articles examine the collection and use of clinical trial data.


CLINICAL TRIALS. CONCERNS OF THE PATIENT AND THE PUBLIC. This paper explores patient and public attitudes toward clinical trials, the use of surrogates (physicians and patients) to determine whether a clinical trial is acceptable, and other empiric data available on this issue. The limited information that is available suggests that the concerns of patients and the public must be addressed if clinical trials are to be successful in recruitment of adequate numbers of subjects to answer important clinical research questions. Ganz, P. A. (1990). Cancer, 65 (10 Suppl.), 2394 – 2399.

CANCER GENETICS NETWORK. The National Cancer Institute is developing an innovative National Cancer Genetics Network to foster collaborative research and integration of research findings into medical practice. This article describes the design and implementation of the project. Stephenson, J. (1998). The Journal of the American Medical Association, 280 (11), 957.
**Pain Management**

Patients can experience many different types and sources of pain as a result of breast cancer. Some pain is acute, such as pain around a surgical site. Other pain may be more chronic, such as that associated with bone metastasis and necrosis of connecting tissue. Managing pain is an important part of ongoing cancer care and can have a great influence on quality of life for breast cancer patients.


**HOW TO USE THE NEW AHCPR CANCER PAIN GUIDELINES.** This document provides information about how to recognize clinical situations in which the Agency for Health Care Policy and Research (AHCPR) cancer pain guidelines can be applied and how to interpret the AHCPR guidelines when discussing cancer pain management with colleagues and family members. It also includes material pertaining to the moral, legal, and ethical responsibility of health care professionals to accept the patient’s report of pain. McCaffery, M. & Ferrell, B. R. (1994). American Journal of Nursing, 94 (7), 42 – 47.


**THE MANAGEMENT OF CHRONIC PAIN IN PATIENTS WITH BREAST CANCER.** This article presents guidelines to help health professionals develop optimal strategies for controlling the chronic pain caused by breast cancer. It recommends an evaluation using the patient’s history and physical examination as well as identifying psychosocial and emotional factors. Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. (1998). Canadian Medical Association Journal, 158 (Suppl. 3), 71 – 81.
Follow–up Care

Patients are enjoying longer survivorship because cancers are being detected at earlier, less invasive stages. Many patients can return to normal activities and primary health care after the acute phase of cancer treatment. What kind of follow-up monitoring are recommended for breast cancer survivors, and how does their breast cancer status affect their other health care?

“I CAN COPE ALUMNI” GROUP HELPS WITH ONGOING PATIENT CONCERNS. This article discusses the implementation and usefulness of an ongoing support group for persons who have participated in the American Cancer Society’s “I Can Cope” education program. In addition to the support that this group offers to patients, the group operates as a feedback source for the hospital staff. Group members review patient education materials and assist with planning other outreach and education efforts. The authors conclude that this group can be mutually beneficial to patients and staff. Cartwright, F. & Facciponti, C. (1994). Oncology Nursing Forum, 21 (3), 600.

IMPACT OF FOLLOW-UP TESTING ON SURVIVAL AND HEALTH-RELATED QUALITY OF LIFE IN BREAST CANCER PATIENTS. A MULTICENTER RANDOMIZED CONTROLLED TRIAL. In this study, patients were randomly assigned to an intensive surveillance, or to a control regimen, in which patients were seen by their physicians at the same frequency, but only clinically indicated tests were performed. No significant differences were found in time to detection of recurrence between the two groups. The results support the view that a protocol of frequent laboratory tests after primary treatment for breast cancer does not improve survival or influence health-related quality of life. The GIVIO Investigators. (1994). Journal of the American Medical Association, 271 (20), 1587 – 1592.

FOLLOW-UP AFTER TREATMENT FOR BREAST CANCER. This article presents guidelines to assist patients and their physicians in arriving at the most effective follow-up strategy after treatment for breast cancer. Outcomes include survival, metastasis-free survival, local recurrence, and quality of life. Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. (1998). Canadian Medical Association Journal, 158 (Suppl. 3), 65 – 70.

CLINICAL PRACTICE GUIDELINES AND COMMENTARIES

Guideline Development

Clinical guidelines are used as a means of assisting physicians in making therapeutic decisions. However, guideline implementation may also reflect the goals of managed care to promote practice conformity and reduce the cost of care. This section describes the process of guideline development in an integrated health care system.

A REGIONAL APPROACH TO THE DEVELOPMENT OF CLINICAL PATHS THAT SPAN THE CONTINUUM OF CARE. This chapter discusses the implications for hospitals and health care providers who are designing and redesigning patient care practices. The

**THE ASCO EXPERIENCE WITH EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES.** This article explores the process by which American Society of Clinical Oncology (ASCO) guidelines are drafted, as well as problems with these guidelines. The authors include suggestions for ASCO and other professional groups that anticipate framing a set of guidelines. **Smith, T. J. & Somerfield, M. R. (1997). Oncology, 11 (11A), 223 – 227.**

**THE ROLE OF ONCOLOGY CLINICAL PRACTICE GUIDELINES IN THE MANAGED CARE ERA.** This article describes the process of developing two common types of guidelines used in oncology: path guidelines and boundary guidelines. The authors state that guidelines should incorporate not only standard outcome measures such as survival but, if feasible, quality of life measures, patient preferences, and cost-effectiveness analyses. **Winn, R. J. (1995). Oncology, 9 (11), S177 – S183.**

**DO CLINICAL PRACTICE GUIDELINES DEFINE GOOD MEDICAL CARE? THE NEED FOR GOOD SCIENCE AND THE DISCLOSURE OF UNCERTAINTY WHEN DEFINING ‘BEST PRACTICES’.** This article reviews methods for developing practice guidelines. The author states that guideline use may negatively impact patients where there are uncertainties in scientific evidence, biases in guideline development, and patient heterogeneity. **Woolf, S. H. (1998). Chest, 113 (3 Suppl.), 166S – 171S.**

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**Guideline Adherence**

*Numerous studies assess how well physicians and other medical staff adhere to guidelines. These studies indicate that physicians are more likely to follow guidelines their peers develop and for which tangible outcomes have been proven. Studies have also found that local guideline development and dissemination alone have minimal effect on clinician acceptance or use. Public and peer pressure, hospital organizational structure and regulations, and state laws have been more effective in influencing physician behavior.*

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**EXTENDING THE APPLICATION OF CRITICAL PATH METHODS.** This article details how, using the full set of critical path methods commonly used in other industries, patient care and resource management can be further improved in health care organizations. **Coffey, R. I., Othman, J. E. & Walters, J. I. (1995). Quality Management in Health Care, 3 (2), 14 – 29.**

**THE QUALITY OF CARE FOR TREATMENT OF EARLY STAGE BREAST CARCINOMA: IS IT CONSISTENT WITH NATIONAL GUIDELINES?** The authors assessed compliance with National Institutes of Health standards of care for early stage breast carcinoma for women treated in two states. In the states studied, practice appears to be consistent with the results of national consensus conferences and clinical trials regarding the treatment of early stage breast carcinoma. **Guadagnoli, E., Shapiro, C. L., Weeks, J. C., Gurwitz, J. H., Borbas, C. & Soumerai, S. B. (1998). Cancer, 83 (2), 302 – 309.**
PHYSICIAN COMPLIANCE WITH OUTCOME-BASED GUIDELINES AND CLINICAL PATHWAYS IN ONCOLOGY. In this paper, outcome-based guidelines and clinical pathways in oncology were developed, implemented, and evaluated in two open-staffed community hospitals. These guidelines and paths were instituted in both the ambulatory and inpatient setting where it was determined that the key to success is the meaningful involvement of physicians. Katterhagen, G. (1996). Oncology, 10 (11), S113 – S121.

CHANGING PRACTICE PATTERNS IN THE MANAGEMENT OF PRIMARY BREAST CANCER: CONSENSUS DEVELOPMENT PROGRAM. The National Institutes of Health studied whether its consensus conference had influenced practice patterns of care given to women with breast cancer. The authors found that the consensus recommendations did not necessarily change physicians’ behavior and that quality of care in diagnosis and treatment of breast cancer still needs to be addressed. Kosecoff, J., Kanouse, D. E. & Brook, R. H. (1990). Health Services Research, 25 (5), 809 – 823.

MAPPING CARE. This study is an examination of how critical paths utilized by health care organizations reflect both differences in care management as well as diverse views over the definition and scope of critical paths. Critical paths are described within a context of continuous improvement and system-wide clinical integration. Lumsdon, K. & Hagland, M. (1993, October 20). Hospitals & Health Networks, 34 – 40.

QUALITY OF LIFE

As increasing numbers of women are surviving breast cancer, the focus of care has shifted from acute treatment-related side effects to long-term effects associated with changes in quality of life (QOL). Almost 2 million breast cancer survivors reside in the United States. An increase in consumer advocacy and media attention to this disease has helped bring breast cancer survivorship to the forefront of public attention. These articles detail the indicators of survivorship: daily functioning, emotional support, and overall well being.

Overview

QUALITY OF LIFE IN BREAST CANCER. PART I: PHYSICAL AND SOCIAL WELL BEING. This two-part article presents the results of a qualitative, descriptive study evaluating the QOL of 21 breast cancer survivors. Part I of this article describes the impact of breast cancer on the physical and social domains of QOL based on in-depth interviews with breast cancer survivors. Ferrell, B. R., Grant, M., Funk, B., Otis-Green, S. & Garcia, N. (1997). Cancer Nursing, 20 (6), 398 – 408.


Planning Support Services

Breast cancer survivors experience many demands of illness across the physical, psychological, social, and spiritual domains. Long-term survivors of breast cancer are challenged with quality-of-life issues including fear of recurrence, family distress, menopause, infertility, and uncertainty. Services that assist patients with these issues are important to recovery. These articles offer insight into the planning and development of QOL support services.

TIPS FOR SUCCESS. This short article provides practical tips for beginning and maintaining patient support groups. The authors suggest ways to set an atmosphere that encourages optimism, caring, and sharing. Information on patient education materials, audio-visual resources, and patient libraries are also briefly discussed. Faciponti, C. A. & Cartwright, F. (1990). *Oncology Nursing Forum*, 17 (4), 620.


QUALITY OF LIFE IN BREAST CANCER SURVIVORS: IMPLICATIONS FOR DEVELOPING SUPPORT SERVICES. This article discusses a cancer center’s attempt to evaluate the quality-of-life needs of breast cancer survivors in order to provide improved supportive care services. The study’s findings may be useful in directing efforts to provide comprehensive care for breast cancer survivors. Ferrell, B. R., Grant, M. M., Funk, B. M., Otis-Green, S. A. & Garcia, N. J. (1998). *Oncology Nursing Forum*, 25 (5), 887 – 895.

EFFECT OF PSYCHOSOCIAL TREATMENT ON SURVIVAL OF PATIENTS WITH METASTATIC BREAST CANCER. This article presents a 10-year follow-up of the effect of psychosocial intervention on breast cancer disease progression and mortality among 86 patients with metastatic breast cancer. In the study, patients with metastatic breast cancer who participated in weekly group therapy for a year lived significantly longer than controls, by an average of nearly 18 months – a difference that was statistically and clinically significant. Spiegel, D., Bloom, J. R., Kraemer, H. C. & Gottheil, E. (1989). *Lancet*, 2 (8668), 888 – 891.
Evaluating Patient Needs

This section reviews the kind of services and programs that can be developed to identify and support patient needs. Assessing needs on an individual basis and without being too time consuming is an important concern when planning and evaluating treatment.


QUALITY OF LIFE AFTER BREAST CANCER: A DECADE OF RESEARCH. The authors describe research ranging from the clinical assessment of the rehabilitation needs of breast cancer patients to a predictive model for the identification of women at risk for psychosocial distress in the year after breast cancer. This work includes descriptive information about the recovery of women after a diagnosis of breast cancer, and the dimensions of quality of life affected by breast cancer and its treatment. Ganz, P. A. & Coscarelli, A. (1995). In J. Dimsdale & A. Baum (Eds.), Quality of Life in Behavioral Medicine Research (pp. 97 – 113). NJ: Lawrence Erlbaum Associates.

DETERMINANTS OF NEED AND UNMET NEED AMONG CANCER PATIENTS RESIDING AT HOME. De-hospitalization of cancer treatment, particularly for those with advanced disease, can complicate adjustment and strain the capacity of caregiver networks to meet patients’ daily needs. This study describes the physiological and social determinants of need and unmet need for assistance among cancer patients in outpatient treatment. Unmet need was primarily associated with the patients’ social support system. The findings call for outpatient staff to evaluate patients’ informal care resources, symptoms, and impairments for home care service referral. Mor, V., Allen, S. M., Siegel, K. & Houts, P. (1992). Health Services Research, 27 (3), 337 – 360.

Treatment Choices

Research in physician communications and patient satisfaction indicates that patients do better and are more satisfied when they participate in making decisions about their treatment. Assessing quality of life and individual circumstance is especially important when treatment options may significantly alter the patient’s appearance and/or functioning. These articles provide background to the connection between quality of life and treatment choice.

PATIENT PARTICIPATION IN TREATMENT DECISION MAKING AND THE PSYCHOLOGICAL CONSEQUENCES OF BREAST CANCER SURGERY. This study examined the extent to which patient participation in the choice of surgical options was related to psychological functioning, fear of cancer recurrence, and aspects of treatment satisfaction three and 13 months postoperatively. It found few associations with degree of participation in treatment decision-making or type of surgical treatment after three months. After 13 months, however, women with greater levels of input into their treatment plan were more


**ETHICAL CONSIDERATIONS IN ONCOLOGY: BALANCING THE INTERESTS OF PATIENTS, ONCOLOGISTS, AND SOCIETY.** The ethical principle of providing as much information as needed for appropriate decision-making applies to both traditional medical care and the need for patients to be involved in the economics of care. This article includes a focus on patient centered quality of life and how helpful it is to point out issues of patient respect and autonomy when there is disagreement. Smith, T. J. & Bodurtha, J. N. (1995). *Journal of Clinical Oncology, 13*(9), 2464 – 2470.

**PATIENT PARTICIPATION IN DECIDING BREAST CANCER TREATMENT AND SUBSEQUENT QUALITY OF LIFE.** This investigation of patients with early breast cancer examined patient involvement in deciding treatment and subsequent health-related quality of life. Six and 12 months following treatment, the patients who believed they were more responsible for treatment decisions and believed they had more choice of treatment reported higher levels of quality of life than did the patients who perceived themselves to have less decision control. Street, Jr., R. L. & Voigt. B. (1997). *Medical Decision Making, 17*(3), 298 – 306.

*Psychosocial Issues Pertaining to Quality of Life*

The psychosocial impact of breast cancer has been extensively studied, and a number of investigators have attempted to characterize women who are at high risk for increased psychosocial morbidity. The articles in this section explore the psychosocial concerns of patients, how they change over time, and how interventions can be designed that lower the risk of morbidity.

**BREAST CANCER SURVIVORS: PSYCHOSOCIAL CONCERNS AND QUALITY OF LIFE.** This article describes the psychosocial concerns and quality of life of breast cancer survivors evaluated two and three years after primary treatment. Breast cancer survivors appear to attain maximum recovery from the physical and psychological trauma of cancer treatment by one year after surgery. A number of aspects of QOL and rehabilitation problems worsen after that time. Nevertheless, breast cancer survivors rate their QOL more favorably than outpatients with other common medical conditions, and they identify many positive aspects from the cancer experience. Ganz, P. A., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M. L. & Petersen, L. (1996). *Breast Cancer Research and Treatment, 38*(2), 183 – 199.
EXPLORING THE INFLUENCE OF MULTIPLE VARIABLES ON THE RELATIONSHIP OF AGE TO QUALITY OF LIFE IN WOMEN WITH BREAST CANCER. This paper explores the relationship between age, psychosocial status, and quality of life in a sample of newly diagnosed breast cancer patients. Based on the literature, a positive relationship between age and psychosocial status was predicted, but the relationship between age and quality of life was uncertain. Among sub-groups examined according to marital status and type of surgery, a positive relationship between age, psychosocial status, and quality of life was observed only in married women who received segmental mastectomy. Ganz, P. A., Lee, J. J., Sim, M. S., Polinsky, M. L. & Schag, C. A. (1992). *Journal of Clinical Epidemiology, 45*(5), 473 – 485.

QUALITY OF LIFE IN LONG-TERM SURVIVORS OF ADULT-ONSET CANCERS. This paper describes research on the quality of life in long-term cancer survivors to identify quality-of-life concerns in this population. Most studies showed that many survivors continue to experience negative effects of cancer and/or treatment on their daily lives well beyond the completion of therapy. Several reports documented positive coping strategies and enhanced QOL in long-term cancer survivors, supporting the need to measure positive aspects of QOL as well as problems in this population. Gotay, C. C. & Muraoka, M. Y. (1998). *Journal of the American Cancer Institute, 90*(9), 656 – 667.

QUALITY OF LIFE AND BREAST CANCER SURVIVORS. PSYCHOSOCIAL AND TREATMENT ISSUES. This study was conducted to determine the relationship between social support, extent of breast cancer surgery, length of time since surgery, geographic location, and overall QOL in breast cancer survivors. These findings demonstrate that social support plays a vital role in promoting overall QOL in breast cancer survivors. Lee, C. O. (1997). *Cancer Practice, 5*(5), 309 – 316.

PSYCHOSOCIAL ASPECTS OF BREAST CANCER. This article provides an overview of the psychosocial aspects of breast cancer. Common psychological reactions during detection, diagnosis, and treatment include anxiety, denial, anger, and depression. The advent of genetic testing poses a whole set of psychological and social issues which primary care providers will need to be aware of in the future. Suggestions for primary care provider interventions such as providing education and support are discussed. Oktay, J. S. (1998). *Lippincott’s Primary Care Practice, 2*(2), 149 – 159.

Sexual Functioning and Spousal Relationships

Breast cancer often changes the dynamics of the patient’s relationship with her significant other. How the changes in these relationships influence both the overall quality of life for the patient and her recovery may be considered when planning treatment.

ADJUSTMENT OF HUSBANDS AND WIVES TO BREAST CANCER. The author explores selected elements within the spousal relationship among women treated for breast cancer within the past three years including fear of recurrence and emotional distress. This study adds to a growing body of information supporting the need to view women who have had breast cancer and their spouses as a unit. Walker, B. L. (1997). Cancer Practice, 5 (2), 92 – 98.

CAREGIVERS

It is especially important to promote the relationship of patients, caregivers, and the medical system in breast cancer care. Caregivers play an important role in assisting with treatment compliance, psychosocial support, and assessing morbidity.

Frequently patients with breast cancer are women who have been in a caregiving role, and with the onset of illness, roles within families change with accompanying stress. Further, because breast cancer treatment can be episodically debilitating, recurrences of the disease can cause increased stress. These articles discuss the role of the caregiver and provide strategies for caregiver communications.

DETERMINANTS OF FAMILY CAREGIVER REACTION. NEW AND RECURRENT CANCER. The authors examined the interaction of patients and caregivers and identified whether changes in new and recurrent patients’ levels of symptoms, functioning, and depression were related to changes in caregivers’ reactions to providing care. They found that the type of disease (new or recurrent) did not impact caregivers reactions to the care they were providing for patients. Given, B. A., Given, C. W., Helms, E., Stommel, M. & DeVoss, D. N. (1997). Cancer Practice, 5 (1), 17 – 24.

THE PREPARED FAMILY CAREGIVER: A PROBLEM-SOLVING APPROACH TO FAMILY CAREGIVER EDUCATION. This paper presents the Prepared Family Caregiver model, which is summarized in the acronym COPE (Creativity, Optimism, Planning, and Expert information). It is designed to teach family caregivers how to develop and carry out orderly plans that address both medical and psychosocial problems and are coordinated with care plans of health professionals. Houts, P. S., Nezu, A. M., Nezu, C. M. & Bucher, J. A. (1996). Patient Education and Counseling, 27 (1), 63 – 73.
HOME CARE

Cancer care has shifted significantly to outpatient and home settings placing more responsibility on family members. Health professionals now rely on family caregivers not only to provide support to the person with cancer, but also to manage medications, help control symptoms and side effects, and report problems that require professional intervention. Health care professionals can construct a plan of care in partnership with the patient and family members by understanding how a particular family responds to meet patient care needs.

FAMILY HOME CARE FOR INDIVIDUALS WITH CANCER. This article describes home care issues from the perspectives of the patient and family members, and proposes strategies that health care professionals can use to improve the outcomes of supportive care for the patient and family. Given, B. A. & Given, C. W. (1994). Oncology, 8 (5), 77 – 83; Discussion 86-8, 93.

Appendix A: Breast Cancer Web Sites

BREAST CANCER TREATMENT DEMONSTRATION
PROJECT PARTICIPATING HOSPITALS

Harlem Hospital Center http://www.uhnyc.org/resource/profiles/harlem.htm
The Long Island College Hospital http://www.lich.org/
Long Island Jewish Medical Center http://www.lij.edu/lij_homepage_ns.html
Lutheran Medical Center http://www.lmcmc.com
New York Community Hospital Web site not currently available
North Shore/Long Island Jewish Health System http://www.interstat.net/nshs/
St. John’s Riverside Hospital http://www.riversidehealth.org/

NEW YORK STATE

Consumers Breast and Cervical Cancer Services – New York State Department of Health http://www.health.state.ny.us/nysdoh/consumer/cancer/cancer2.htm
Consumers Cancer Statistics – New York State Department of Health http://www.health.state.ny.us/nysdoh/research/cancer/cancer.htm
Breast Cancer and Environmental Risk Factors in NYS Cornell University http://www.cfe.cornell.edu/bcerf/
Cancer Registry – New York State http://www.health.state.ny.us/nysdoh/cancer/volume1.htm
New York Race for Cure http://www.nyracefortheicure.org/
Women’s Health Issues – New York State Department of Health http://www.health.state.ny.us/nysdoh/consumer/women/homewome.htm
FEDERAL GOVERNMENT

CDC Office of Women’s Health Home Page
http://www.cdc.gov/od/owh/whhome.htm

CDC Office of Women’s Health Breast and Cervical Cancer Page
http://www.cdc.gov/od/owh/whbc.htm

CDC National Center for Environmental Health Breast Cancer Related Projects

Initiative to Eliminate Ethnic and Racial Disparities in Health
http://raceandhealth.hhs.gov/

NCI’s Breast Cancer Information for Patients
http://cancernet.nci.nih.gov/pat_home.htm

NCI Surveillance, Epidemiology, and End Results
http://www-seer.ims.nci.nih.gov/

NCI Cancer Trials
http://cancertrials.nci.nih.gov/

Medicare & Mammography
http://www.hcfa.gov/stats/mamm/mammover.htm

National Women’s Health Information Center
http://www.4women.gov/g-index.htm

Office of Minority Health Resource Center
http://www.omhrc.gov/frames.htm

US Army Breast Cancer Research Program Home Page
http://140.139.42.104/bcrp/

NATIONAL ORGANIZATIONS

Association of Community Cancer Centers
http://www.assoc-cancer-ctrs.org/

ACS Breast Cancer Network
http://www.cancer.org/bcn/bcnnews.html

American Medical Women’s Association
http://www.amwa-doc.org/

National Action Plan on Breast Cancer
http://www.napbc.org/

National Alliance of Breast Cancer Organizations
http://www.nabco.org/

National Asian Women’s Breast Cancer
http://www.nawho.org/breast.html

National Breast Cancer Coalition Web
http://www.natlbcc.org/

National Coalition for Cancer Survivorship
http://www.cansearch.org/

National Comprehensive Cancer Network
http://www.cancer.med.umich.edu/NCCN/NCCN.html

The March to Conquer Cancer
http://www.themarch.org/

Oncology Nursing Society
http://www.ons.org/

Y-ME National Breast Cancer Organization
http://www.y-me.org/

YWCA National Encoreplus Breast Cancer Site
http://www.ywca.org/mission/health_care.html
INTERNATIONAL

International Union Against Cancer http://www.uicc.org/
Federation of European Cancer Societies http://www.fecs.be/
International Agency for Research on Cancer http://www.iarc.fr/
International Society for Preventive Oncology http://www.cancerprev.org/
Canadian Breast Cancer Network http://www.cbcn.ca/
Le cancer du sein http://www.spieao.u-nancy.fr/serveurfac/EAO_WEB/can_sein/cancer.htm
Scotland: Health Education Board http://www.hebs.scot.nhs.uk/

BREAST CANCER INFORMATION SITES

Breast Cancer Legislation–USA http://members.aol.com/BCLEGIS/index.htm
Cancer Research Foundation of America http://www.preventcancer.org/breastcancer.html
Steve Dunn’s Cancerguide Information Page http://cancerguide.org/
Mammacare(R) Teaching Breast Examinations http://www.mammacare.com/
Mautner Project Web Page http://www.mautnerproject.org/
NIDL Breast Cancer Initiative http://www.nml.org/BreastCancer/
CLEARINGHOUSES

ACCC Cancer Resource Line http://www.assoc-cancer-ctrs.org/resources.html
Breast Cancer Awareness and Solutions Network (BCASN) http://216.104.144.179/content/default.asp
Susan G. Komen Breast Cancer Foundation http://www.breastcancerinfo.com/
NCI’s CancerNet Cancer Information http://cancernet.nci.nih.gov/
Stanford Community Breast Health Project http://www-med.stanford.edu/CBHP/
Your American Cancer Society Cancer Resource Center http://www.cancer.org/bottomcancinfo.html
Health Answers Women’s Health http://www.healthanswers.com/
National Information Center on Health Services Research and Health Care Technology http://text.nlm.nih.gov/ftrs/gateway
NCI CancerNet Database http://imsdd.meb.uni-bonn.de/cancernet/cancernet.html

RESEARCH JOURNALS

American Medical Association http://www.ama-assn.org/
Breast Cancer Research and Treatment http://www.wkap.nl/journalhome.htm/0167-6806
JAMA Women’s Health Information Center http://www.ama-assn.org/special/womh/
Science Magazine http://www.sciencemag.org/
BCASN On-Line Articles http://216.104.144.179/content/providers/MedicalEd/med1.asp
A Comprehensive Review of Literature and Web Resources

**CLINICAL PRACTICE GUIDELINES/ BEST PRACTICES**

AHCPR Clinical Information  
http://www.ahcpr.gov/clinic/

AHCPR Clinical Practice Guidelines  
http://text.nlm.nih.gov/ftsr/pick?collect=ahcpr&dbFrom=0&db=0&cc=1&t=906650929

ASCO Breast Cancer Clinical Practice Guidelines  

Australian National Breast Cancer Centre Clinical Practice Guidelines for Management Early Breast Cancer  

Best Practice Network  
http://www.best4health.org/

Canadian Medical Association Clinical Practice Guidelines  

Institute for Health Care Improvement  
http://www.ihi.org/

The Picker Institute  
http://www.picker.org/

NCCN Oncology Practice Guidelines  
http://www.cancernetwork.com/indexes/nccn.htm

**CONSUMER INFORMATION**

Avon’s Breast Cancer Awareness  
http://www.avoncrusade.com/

Breast Cancer Information Service  
http://trfn.clpgh.org/bcis/

Cancer Care, Inc.  
http://www.cancercareinc.org/

Corporate Angel Network  
http://www.CorpAngelNetwork.org/

EduCare- Cancer Help- Breast Cancer  
http://www.cancerhelp.com/ed/

The Feminist Majority Foundation  
http://www.feminist.org/other/bc/bchome.html

The Breast Cancer Round Table  

Harvard Health Publications  
http://www.harvardhealthpubs.org/

Lifetime Online: Welcome to the Women’s Health Center  

Lippincott-Raven Publishers  
http://www.lrupub.com/

Living Beyond Breast Cancer  
http://www.dvbiznet.com/lbbc/

Time Magazine On-line: Your Health  
http://cgi.pathfinder.com/time/personal/health.html

New York Times Women’s Health Page  

New York Times Women’s Health Resources  
http://www.nytimes.com/specials/women/whome/resources.html#breast_cancer

New York Times Your Health Daily  
http://nytsyn.com/IMDS|YHD Cancer 2|index

Oncolink Breast Cancer: General Information  
http://oncolink.upenn.edu/disease/breast/

University of Louisville Breast Cancer Online  
http://breast-care.louisville.edu/breast-care/

Virtual Hospital Patient Information  
http://www.vh.org/Patients/IHB/OrgSys/Breast.html


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SURVIVORSHIP/SUPPORT GROUPS

Adelphi University New York Statewide Breast Cancer Support Hotline  
http://icculus.adelphi.edu/bcancer/

Catholic Health Association of America Supportive Care  
http://www.chausa.org/MISSSVCS/EXECSUM.ASP

National Coalition for Cancer Survivorship  
http://www.cansearch.org/

NIH Office of Cancer Survivorship  
http://ctep.info.nih.gov/HTML%20Files/Off_Cancer_Survivorship.htm

NCI Patients Breast Cancer Quality of Life  
http://cancernet.nci.nih.gov/quality.htm

NCI Transitional Care Planning Page  

Oncolink: Medical Supportive Care for the Cancer Patient  
http://oncolink.upenn.edu/support/

SHARE – Self-Help for Women with Breast Cancer  
http://www.sharecancersupport.org/

Celebrating Life  
http://www.celebratinglife.org/

Keepin’ the Faith Cancer Support Group  
http://ktf.org/

Welcome to Breast Cancer Lighthouse  
http://commtechlab.msu.edu/sites/bcl/

BREAST CANCER LINK SITES

Association of Cancer Online Resources, Inc.  
http://www.acor.org/

ASCO Internet Resources  
http://www.asco.org/people/rs/html/f_ir.htm

BEST WEB SITES on BREAST CANCER Version 1.8  
http://darkwing.uoregon.edu/~jbonine/bc_sources.html

BreastCancerNet Links: Web Sites  
http://www.breastcancer.net/cgi/bcn.web.wcgi

Canadian Breast Cancer Network  
http://www.cbcn.ca/linksindex.html

Cancer and Women’s Health Links  
http://www2.cybernex.net/~sune/blinks.html

CancerNews Breast Cancer Links  
http://www.cancernews.com/breast.htm

CDC Cancer Links  
http://www.cdc.gov/ncddphp/dcpc/linksalt.htm#breast

EORTC External Links  

HANYS Womens Health Links  
http://www.hanys.org/resource/links/womens.htm

The Healthcare Metropolis  
http://www.healthmetro.com/

Healthtouch® – Online for better health  
http://www.healthtouch.com

Healthweb Oncology  
http://www.medlib.iupui.edu/hw/onco/

International Guide to Internet Resources for Cancer  
http://www.ncl.ac.uk/~nch/www/guides/clinks1.htm

MA Links – Breast Cancer  
http://www.breasted.org/links.html

NAPBC Web Information Resources  
http://www.napbc.org/napbc/websites.htm

NCI Seer Other Links  
http://www-seer.ims.nci.nih.gov/OtherLinks.html

NNLM Guide to Internet Discovery Tools  

PSL Internet Medical Resources  
http://www.pslgroup.com/medres.htm
A Comprehensive Review of Literature and Web Resources

**USAMRMC Breast Cancer Research Program Links**
http://140.139.42.104/bcrp/links.html

**WWW Virtual Library Biosciences Medicine**
http://www.ohsu.edu/ cliniweb/wwwvl/

**Yahoo! Full Coverage - Breast Cancer Research**
http://headlines.yahoo.com/Full_Coverage/Tech/Breast_Cancer

### BREAST CANCER SEARCH ENGINEs

**ASCO Search Engine**
http://www.asco.org/people/sh/f_sh.htm

**“InteliHealth – Home to Johns Hopkins Health Information - Breast Cancer”**
http://www.intelihealth.com/IH/ihTheH?t=8293&p=-br,IHW|~st,408|~r,WSIW000|~b,*|&st=8096

**Medical Matrix**
http://www.medmatrix.org/index.asp

**Medscape’s Women’s Health Page**

**MedWeb: Oncology**

**NCI Healthfinder Links Page**
http://www.healthfinder.gov/tours/brcancer.htm

**Starting Point: Health On-line**
http://www.stpt.com/health/health.html

**UK Newcastle InterNet Resources for Cancer**
http://www.ncl.ac.uk/~nchwww/guides/clinks1.htm

**Yahoo! Health: Diseases and Conditions: Breast Cancer**
http://www.yahoo.com/Health/Diseases_and_Conditions/Breast_Cancer/

### NATIONALLY RECOGNIZED CANCER CENTERS

**M. D. Anderson Cancer Center**
http://www.mdacc.tmc.edu/

**Arizona Cancer Center**
http://www.azcc.arizona.edu/

**Cedars-Sinai Comprehensive Cancer Center**
http://www.csccc.com/

**Duke University Comprehensive Cancer Center**
http://www.cantr.mc.duke.edu/

**The John Hopkins Breast Center**
http://www.med.jhu.edu/breastcenter/

**Fred Hutchinson Cancer Research Center**
http://www.fhcr.org/

**Harvard’s Dana Farber Cancer Institute**
http://www.dfcı.harvard.edu/site1/NS4Index.asp

**H. Lee Moffit Cancer Center and Research Institute**
http://daisy.moffitt.usf.edu/

**Memorial Sloan-Kettering Cancer Center**
http://www.mskcc.org/

**UCLA Breast Center**
http://www.medctr.ucla.edu/hlthcareprov/factshet/BREASTCR.HTM

**University of Michigan Comprehensive Cancer Center**
http://www.cancer.med.umich.edu/
BREAST CARE CENTERS

CPMCnet, Columbia Presbyterian Medical Center  http://cpmcnet.columbia.edu/
Hartford Hospital CHESS  http://www.harthosp.org/cancer/chess.html
The Johns Hopkins Breast Center  http://www.med.jhu.edu/breastcenter/
Mayo Clinic Breast Cancer Page  http://www.mayohealth.org/mayo/common/htm/canhpage.htm
The New York Hospital – Cornell Breast Center  http://surgery.med.cornell.edu/breast/breast.htm
Our Lady of Lourdes Health System  http://www.lourdes.com/
University of Wisconsin Breast Cancer  http://www.medsch.wisc.edu/bca/bca.html

UNIVERSITY SERVICES

M. D. Anderson Oncolog  http://www.mdacc.tmc.edu:80/~oncolog/
Breast Cancer: Ask NOAH  http://www.noah.cuny.edu/cancer/breastcancer.html
Columbia Univ. Special Concerns of Women  http://cpmcnet.columbia.edu/texts/guide/toc/toc09.html
OncoLink: Journals and Newsletters  http://oncolink.upenn.edu/journals/
UCSF Potential Benefits and Risks of Mammograms  http://mammography.ucsf.edu/inform/index.cfm

HEALTHCARE ORGANIZATIONS/INSTITUTES

American College of Physician/American Society of Internal Medicine  http://www.acponline.org/
American College of Radiology  http://www.acr.org/
CenterWatch Clinical Trials Listing Service  http://www.centerwatch.com/
Susan G. Komen Breast Cancer Foundation  http://www.komen.org/
Welcome to CHESS  http://chess.chsra.wisc.edu/Chess/
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