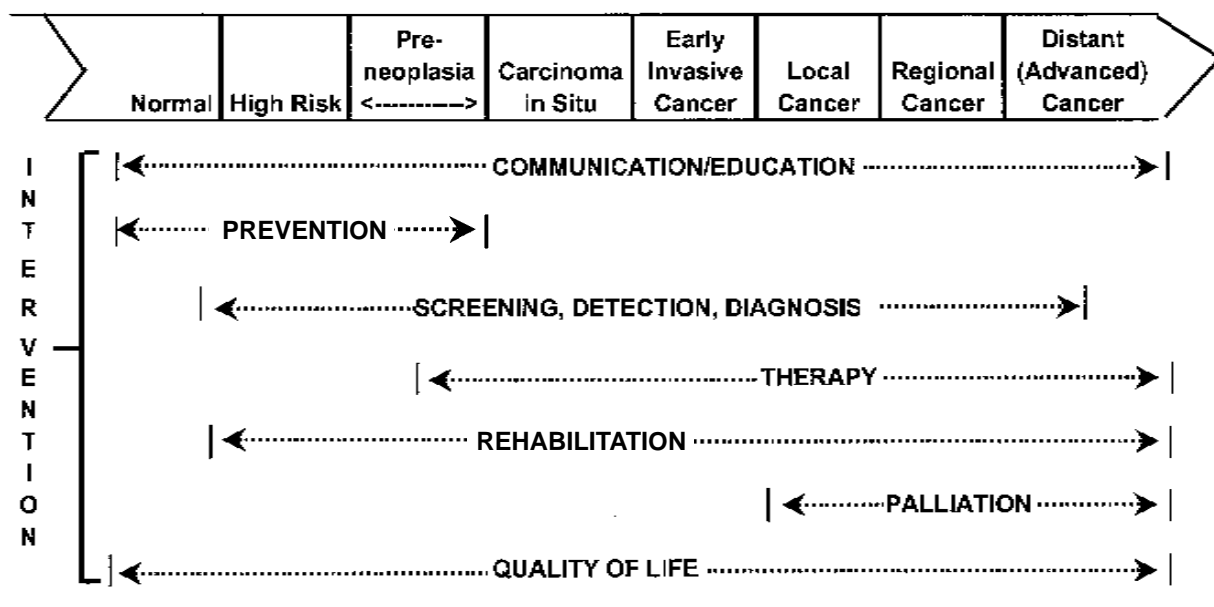

BREAST CANCER PROFILE FOR KENTUCKY

Introduction

This profile of information currently available about breast cancer in Kentucky is presented in sections focusing on prevention, early detection, treatment, and quality of life. These are the major interventions which are currently employed to reduce the incidence, morbidity and mortality of breast cancer. The relationship of these interventions to the course of the disease is illustrated in Figure 1.

Figure 1. Overview of Interventions for Breast Cancer Course of Disease



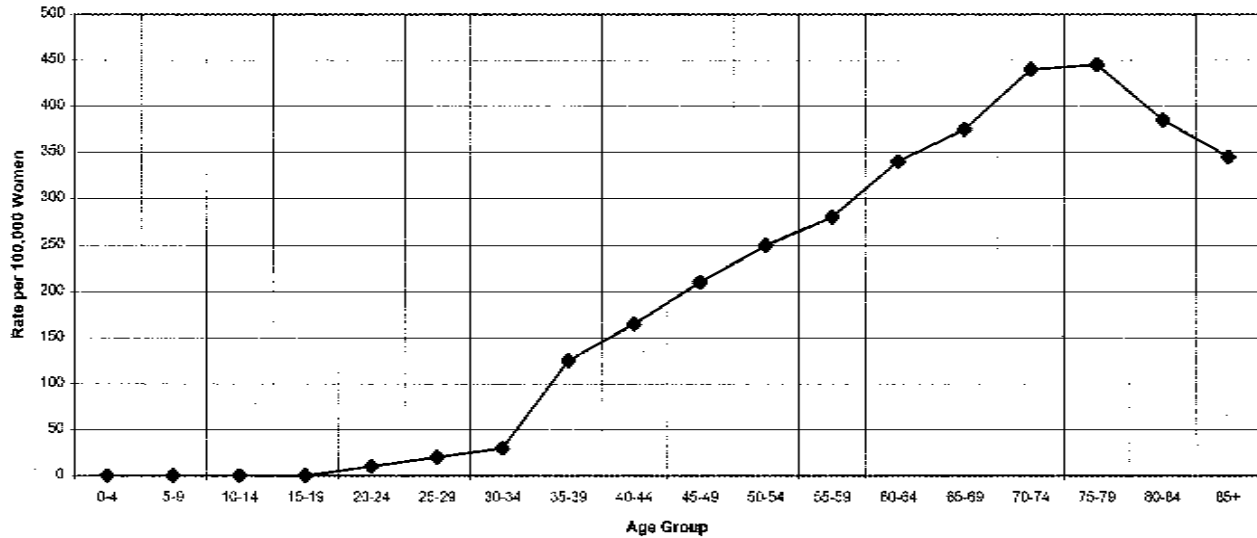
Source: Friedell, GH, Linville, LH, Rubio, A, Wagner, WD, Tucker, TC. What providers should know about community cancer control. *Cancer Practice*; 1997;5(6):367-374.

These sections also contain a discussion of the data which the Task Force was not able to obtain. In some instances the data items have not been collected in a systematic fashion. In other instances the data have been collected in various ways by physicians or health care facilities, but were not accessible for this report, e.g., data concerning mammography are collected, but not reported by each FDA - approved facility.

Breast Cancer Incidence. In 1996, 2817 Kentucky women were diagnosed with breast cancer. The age-adjusted incidence rate (the rate of occurrence) in 1996 was 113.0 per 100,000 women. The US age-adjusted rate for 1995, the latest one reported by the NCI Surveillance, Epidemiology and End Results (SEER) Program was 111.3 per 100,000 women.

The Kentucky age-specific incidence rates for the period 1992-1996 clearly illustrate the importance of age as a major risk factor (Figure 2). The 1996 incidence of breast cancer in the 15 Area Development Districts is illustrated in Table 1. (See also - Appendix B)

Figure 2. Age-Specific Incidence Rates per 100,000 Women, 1992-1996



Source: Kentucky Cancer Registry, 1997 Incidence Report

Table 1. Area Development Districts Age-Adjusted Incidence Rates of Breast Cancer

Area Development District	Total Age-Adjusted Cases	Rate
Gateway	58	134.92
Lincoln Trail	167	128.51
Kentucky River	92	126.22
Bluegrass	489	125.97
Buffalo Trace	41	121.83
KIPDA	659	119.55
Purchase	170	118.45
Green River	162	111.97
Lake Cumberland	141	109.51
Pennyrile	140	103.31
Barren River	156	98.40
Cumberland Valley	147	98.24
Northern Kentucky	218	97.68
Big Sandy	95	91.17
FIVCO	82	89.50
TOTAL	2817	112.96

Source: Kentucky Cancer Registry, 1997 Incidence Report

Early Versus Late Stage Breast Cancer. From the Kentucky Cancer Registry, the number of newly diagnosed breast cancer patients is available each year; cancer is recorded as incidence of an early or a late stage diagnosis. For the six-year period 1991-1996, whites consistently had a higher percentage of early-diagnosed cancer (68.3%) than African Americans (58.1%). The percent of breast cancers diagnosed during 1995-96 at the late stage varied greatly across regions of Kentucky, from less than 24 percent of cases to over 40 percent (Appendix B). Women with higher educational levels utilize mammography more and are diagnosed with earlier stage disease. Regional data suggest that women at risk for late stage diagnosis have lower educational attainment and lower incomes.

Educational attainment ranges widely in the state with some regions in which a significant part of the adult population has not graduated from high school or even gone past the ninth grade. From the 1990 census, the latest census data available, educational levels of women 18-24 and of women 25 and older show that the younger age group tends to have a higher percentage of high school graduates. The percentage of women age 25 and older without at least a high school education ranges from 55 percent in Owsley County to 17 percent in Oldham County. Regions with the lowest educational levels (40 - 45% of women with no high school education) are found in southeastern Kentucky. The same counties had the highest percentages (27 - 35%) of women in poverty. There is a close correlation between educational attainment and poverty across all regions.

Breast Cancer Mortality. Early detection of breast cancer mitigates between breast cancer occurrence and the death rate from breast cancer. Breast cancer is more likely to be diagnosed in early stages in central Kentucky counties that had the highest overall incidence rates, but the second highest death rates. Women were more likely to be diagnosed in late stage in eastern and far western counties, areas that had the highest death rates.

In 1995, 631 Kentucky women died of breast cancer. In 1995, according to data from the Centers for Disease Control and Prevention (CDC), Kentucky ranked 30th among the states in the age-adjusted death rate from breast cancer. The Kentucky death rate was 24.2 per 100,000 women compared to the two highest death rates of 33.8 in the District of Columbia and 28.5 in Montana. Mortality rates varied among the 15 Area Development Districts, with the highest rates in northeastern, north central, and far western Kentucky.

Prevention

Prevention, also known as primary prevention, is defined as the inhibition of disease development before it occurs. The major risk factors for breast cancer, as found in national research, are older age, family history of breast cancer, and age at first pregnancy (no children or having the first child at a late age).

Prevention Trials for High Risk Women. Two national prevention trials are being conducted in Kentucky. The drug tamoxifen was compared to a placebo in a study to see whether breast cancer can be prevented in high risk women. This study involved 13,338 women in the United States and Canada. About 65 Kentucky women were involved through Norton Healthcare in Louisville and the University of Louisville, and about 140 Kentucky women were involved through the University of Kentucky. On the national level, 85 cases of breast cancer were reported among women taking tamoxifen and 154 cases of breast cancer were reported in the placebo group; it was shown that tamoxifen reduced new breast cancers by 48 percent.

Another national prevention trial involving the drug raloxifene has just begun; therefore, information regarding the number of Kentucky women involved in this study was not available. This prevention study will compare the effects of raloxifene and tamoxifen in high risk women and will involve about 22,000 postmenopausal women in the United States and Canada. Three Kentucky sites have been approved- the University of Kentucky, the University of Louisville, and Norton Healthcare.

Genetic Testing is a relative new approach being encouraged for women with familial histories of breast cancer. Although breast cancer has not proven to be a preventable disease, women with a genetic predisposition should more closely monitor any occurrence by practicing breast self examination and having regularly scheduled clinical breast exams and mammograms. Inheritance of an altered or mutated copy of one of two genes-BRCA1 and BRCA2-may result in up to ten percent of female breast cancers. A woman who inherits a faulty copy of the BRCA1 gene has an 87 percent chance of developing breast cancer by age 70. To date, 39 Kentucky women have undergone BRCA gene testing, according to Myriad Genetic Laboratories. Thirty-five of these tests were paid for by grants and conducted for research purposes and four tests were funded by other means. Kentucky is ranked lowest out of all fifty states in the number of genetic tests done for the BRCA1 and 2 genes, according to Myriad Genetic Laboratories. All Kentucky women who have had the BRCA gene test to date have been white. The test requires a blood sample, and participants must sign an informed consent form and receive genetic counseling prior to the test. It takes about three weeks to receive the results since the blood work is sent to Myriad Genetic Laboratories in Salt Lake City. The test costs \$2400 for full-sequencing of the BRCA1 and 2 genes,

but subsequent “mutation specific” tests in the same family cost \$395. Ashkenazi Jewish women are charged only \$495 for the initial gene sequencing as opposed to the standard \$2400 because of the limited number of specific gene mutations which can occur in this population.

The Health Insurance Portability and Accountability Act (P.L. 104-191) prohibits health insurers from refusing to renew or continue coverage because of genetic information. The use of genetic information to determine eligibility or set premiums also is prohibited. However, the law offers no protection to uninsured women who apply for individual health insurance coverage or who leave their employer and the group insurance market and do not continue coverage under COBRA.

The University of Kentucky’s HMO has paid for two BRCA genetic tests in full and Blue Cross Blue Shield has paid sixty percent of one patient’s genetic testing costs to date. In appropriate cases, Aetna will pay in full for genetic testing of the BRCA1 and BRCA2 genes. The women considered for the tests are those at high-risk for inherited breast cancer (and ovarian cancer). These women must have a family history of breast cancer, such as two or more blood relatives with premenopausal breast cancer, or be related to a man or woman with a BRCA1 or BRCA2 gene mutation.

Early Detection

Early detection, also called secondary prevention, is defined as finding precursors of a disease or the disease itself at the earliest detectable stage in order to initiate treatment. *Screening mammography* uses a radiology method to detect disease in the absence of symptoms. Although often equated with screening mammography, *diagnostic mammography* is employed to detect disease in the presence of symptoms or suspicious findings on a screening mammogram. Annual screening mammography coupled with a clinical breast exam is the most effective method of early detection of breast cancer in women age 40 and over. Early detection and treatment improves the probability of survival, and prevents the suffering, disability and financial burden that accompany a late diagnosis. The latest NCI SEER data, 1986-93, show that the 5-year survival rate for local breast cancers (98.3%) is nearly five times that of distant cancers (19.9%).

Mammography Goals. Healthy Kentuckians 2000's public health goal for mammography is that by the year 2000 at least 80 percent of women age 50 and over have had a mammogram and clinical breast exam in the last two years. Behavioral Risk Factor Surveillance System (BRFSS) data (1997) from the Kentucky Department for Public Health (KDPH) document that about 65 percent of women age 50 and older reported getting these preventive services within the last two years, with non-whites at 60 percent and whites at 65 percent. Women age 50-59 had the highest rate (72%), followed by those 60-69 (66.5%), and those 70 and older (56.7%).

Even lower rates of screening are found in women with an income below \$20,000/year (47.4%) and in women with either elementary (43.1%) or some high school (45.8%) as their highest educational level attained. Women in the age group 50-64 (65%) had a higher rate of mammograms and clinical breast exams in the past two years than women age 65 and over (54.2%).

According to the CDC, about 30 percent of deaths from breast cancer could be prevented if women age 50 and older received regular mammograms for early detection. In 1995, Kentucky ranked sixth in the nation in the percent of women (35.7%) reporting they had *not* received a mammogram in the past two years, compared to Arkansas at the highest (39.0%).

Breast cancer may be detected early through breast self-exam (BSE) by the woman, clinical breast exam (CBE) by her health professional, through tests such as screening mammography, or diagnostic mammography, ultrasound or other test.

Mammography Facilities. Thirty-eight (32%) of Kentucky counties do not have a certified mammography facility (Appendix B). However, each of the 38 counties has access to at least one mammography facility in a neighboring county. In addition, several mobile mammography units travel into counties without their own facility.

Mammography Coverage. Medicaid, Medicare, and most private insurance plans cover the cost of screening mammograms. There may be restrictions on age and frequency of allowed tests as well as waivers for coverage. The National Health Plan Employer Data and Information Set (HEDIS) which sets standards of data for managed care organizations and is used as a measure of quality by insurance, consumer and employer groups, suggests that the number of women over age 52 who have had a screening mammogram in the last year is a measure of quality of preventive care. Kentucky's Department of Insurance began collecting this measure from Kentucky health plans in March 1999, so data on mammography rates in managed care organizations were not available at the time of this report.

Data on mammograms are available for Kentucky women covered by Medicare. The highest percentage of women having had a mammogram within the last two years¹ reside in the Louisville, Owensboro, and Paducah regions of the state (Appendix B). Regions of the state with highest percentages of these Medicare eligible women getting mammograms also had the highest percentages of women with high school education; these data correspond to the data from the BRFSS for women over 50. The women in southeastern and southern counties had the lowest percentages of mammography. Rates of mammography are higher for white than African American women. However, rates for mammography screening have increased for both African American and white women, although the rate for white women shows a greater increase. Older women, Medicaid eligible, who are receiving long-term care, either at home or in a nursing home facility, face barriers to mammography screening and are a concern as well. Data on the number of Medicaid women receiving mammograms for 1997 were not available.

Mammography Provided Through Kentucky Local Health Departments. In Fiscal Year 1998, KDPH provided in all 120 counties a total of 19,568 mammograms, 17,088 of which were screening mammograms. Nearly 50 percent of all screening mammograms were provided to women over age 50, including 7.8 percent provided to women over age 65. Twenty-five percent of newly diagnosed breast cancer cases are women younger than 50, 75 percent are age 50 and over, and 50 percent are over age 65. Over 100 mammography facilities are contracted within the county of the local health department; 38 health departments contract with providers in another county; 17 counties are visited by the Brown Cancer Center's mobile mammography unit; and four other mobile mammography units serve counties in northern, northeastern and eastern Kentucky. Mammograms are provided at no charge to women with incomes below 100

¹ Screening rates were analyzed for a two year period (1994-1995) because the Healthcare Financing Administration only covered biennial screening mammography until January 1999.

percent of the federal poverty line. Charges for women between 100 percent and 250 percent of poverty follow a sliding fee scale according to income. The Kentucky Department for Public Health pays \$56 for each screening mammogram to the contractual mammography facilities. The average cost of screening, including clinical breast exams, as reported by Kentucky Department for Public Health in Fiscal Year 1998 was \$139 per woman.

According to the Fiscal Year 1998 report of the Kentucky Department for Public Health Breast Cancer Screening program, counties with low screening rates have been targeted to receive flyers promoting mammography for underserved women. The Kentucky Department for Public Health has also provided training funds for the Kentucky Homeplace project, based in the University of Kentucky's Center for Rural Health in Hazard, to train family health care advisors in the importance of early breast and cervical cancer detection. The Kentucky Department for Public Health partners with postmasters, local breast cancer coalitions, the Kentucky Cancer Program, the American Cancer Society, and others in funding community-based outreach activities for early detection. Many special events to raise breast cancer awareness are coordinated throughout the year, including an annual advocacy conference with the Kentucky Breast Cancer Coalition. With Center for Disease Control and Prevention support, the Kentucky Department for Public Health and the Kentucky Cancer Program have established over 30 coalitions in urban and rural communities across the state in cooperation with local health departments. Intervention programs for health care providers to increase breast cancer screening have been developed to complement the activities of the coalitions.

Barriers to Mammography. As identified in national research, women who do not get mammograms cite, as the primary reason, the fact that their doctor did not recommend a mammogram. Other reasons include fear of having cancer, cost of the procedure or lack of insurance coverage, painfulness of the procedure, lack of transportation to the facility, and other reasons. Information from the Kentucky Cancer Program, the American Cancer Society and others is one mechanism encouraging women to get mammograms. Programs with the specific aim of getting more information and support to African Americans include the Sister-to-Sister Program and the Kentucky African Americans Against Cancer.

Some barriers for low-income women who are not covered by Medicaid or other insurance are being addressed through the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. Awards are given to states, which provide matching funds, for screening mammograms and Pap tests for low-income women, for either no charge or a nominal fee based on income. Payment for clinical breast exams and referrals to contractual mammography facilities are provided through the local public health departments.

Kentucky Medical Schools' Training in Cancer Care and Psychosocial Skills with Patients. Lack of physician referral has been cited as the main reason women do not get mammograms. Therefore, a telephone survey of Kentucky medical schools at the University of Kentucky, University of Louisville, and Pikeville Osteopathic Medical School was conducted to determine the extent of training with regard to patient communication strategies for overcoming screening barriers, telling patients bad news, listening to patient concerns, and related psychosocial skills strategies. It was found that although there are informal discussions in seminars and through direct patient-care clerkship training, minimal formal education takes place.

The Kentucky Cancer Program through funding from the Kentucky Department for Public Health has initiated a continuing education program for Kentucky primary care providers to improve communication skills and adherence to breast cancer screening guidelines.

Communication and Education. Critical to the success of any cancer control program, and particularly the control of breast cancer, is the need for the effective transmission of understandable, relevant and meaningful information to the public and effective two-way communication between the public and health care professionals. It has also been recognized that health care providers must take into account the literacy capabilities of patients and their families when discussing any aspect of breast cancer care, particularly the subject of treatment. It is essential that the patient understand all aspects of the care which will be provided to her, and that there be effective communication between patients and care givers regarding any and all issues of concern.

One of the important factors in achieving a high level of information transfer, and the conversion of this information into action, is the level of educational attainment and particularly the level of literacy of the population concerned. Educational attainment does not correlate perfectly with the degree of literacy, but it is at this time the most useful marker.

One consequence of recognizing the regional levels of educational attainment, and presumably the levels of literacy, is the need to have the preparers of educational materials on breast cancer risks, mammography, breast cancer treatment and related issues take these facts under consideration when materials are being prepared. Printed materials cover such subjects as the location of screening facilities, the availability of support groups and support services, and information about other matters important to patients with breast cancer and their families. These materials are available in all counties through the 13 regional offices of the Kentucky Cancer Program, the American Cancer Society regional representatives, local health

departments, and health care facilities. Educational programs on subjects including breast cancer detection, diagnosis and treatment are also generally available, including speakers, audiovisual materials, the presence of a health educator and a variety of printed materials.

Data Limitations. The Behavioral Risk Factor Surveillance System (BRFSS) of KDPH is a national database formed in each state by telephone interviews of a sample of residents. In some Kentucky counties a high percentage of households lack phones. For instance, the percent of households with no phone in the 1990 Kentucky census ranges from 20 percent in the Cumberland Valley and Kentucky River regions of southeastern Kentucky to about five percent in the Louisville and northern Kentucky regions. While the BRFSS survey statistically weights the sample to make up for households without phones, it is quite possible that women in these households, albeit a small number compared to the overall population of Kentucky, would report much lower use of mammography than those who responded.

Another limitation of the data on early detection is the lack of a single source of data on all Kentucky women receiving mammograms. For instance, data are reported separately from Medicaid, Medicare, and KDPH, and will be available for managed care organizations, but no single repository contains information on women covered with private insurance. To understand the total mammography rate in Kentucky, data must be non-duplicated, i.e., individuals should be counted only once (for instance, one might be counted in both health department and Medicaid data). Mammography registry data systems are in use in some states, such as the Carolina Mammography Registry and Data System. The System collects data on all mammograms performed in a state, tracks each screenee's mammogram(s), the results of the screening, and subsequent tests for diagnosis, including pathology reports. Because only one registry exists in states using the system, women are counted only once, and all women receiving mammograms in the state are in the registry. Data are collected on each woman's age, ethnicity, county of residence, health history, and mammography payment source.

Treatment

Treatment for a confirmed case of breast cancer can vary greatly depending on the stage at which the cancer is found, characteristics of the woman and her health, characteristics of the tumor itself, and the characteristics of the health professional treating her. Surgical treatments for breast cancer include lumpectomy, also called partial mastectomy, total mastectomy, modified radical, and radical mastectomy. These options are dependent on the extent of breast and surrounding tissue excised. Other treatments for breast cancer include radiation, chemotherapy, bone marrow transplant and hormone therapy.

Availability of Cancer Specialists in Kentucky. For this report, cancer physicians are defined as board-certified specialists in surgery, medical oncology, radiology, and radiation therapy. Most of these physicians practice in higher-population areas of Kentucky, according to membership lists of board-certified specialists. Louisville and Lexington regions have the greatest cancer specialist supply with 9.7 and 9.5 per 10,000 women in the population. This result is expected because of the presence of large numbers of tertiary care hospitals and a cancer center in each community. Lowest supplies of specialists were found in high poverty areas of Kentucky, such as southeastern and eastern regions, with less than three specialists per 10,000 women. Most other regions averaged between five and seven specialists per 10,000 population.

Standards of Care. Guidelines, protocols, or other standards of care for the treatment of breast cancer at any stage are determined and accepted by various oncology specialty and professional organizations. They are reproduced and made available to members of these professional organizations and others seeking up-to-date treatment guidelines. These standards of care are determined on the basis of all clinical data available for a particular case. They are also subject to change as scientific knowledge and technology advance.

The National Institutes of Health (NIH) periodically produces “consensus statements” in which a panel of experts reviews relevant research and publishes its findings of the diagnostic procedures and the most effective treatments. Since 1977, NIH has published six available statements on various aspects of breast cancer screening, early diagnosis, and chemotherapy. Some statements have been superseded when new research makes them obsolete. The latest consensus development statement (1997) addresses breast cancer screening for women ages 40-49. All NIH statements can be accessed at the web site <http://odp.od.nih.gov/consensus/>. The 1990 statement issued on treatment of early-stage breast cancer recommended lumpectomy, followed by a course of radiation treatment for negative-node women. This guideline states that treatment plans should be tempered by the concern for individual women’s preferences, risks, and prognosis based on considerations of individual anatomy, histologic characteristics of the tumor, psychological issues, and health history.

For breast cancer surveillance and tumor marker guidelines, see the American Society of Clinical Oncologists' web site http://www.asco.org/prof/pp/html/f_gs.htm. Their statement on access to quality cancer care states:

Cancer care requires that the patient has access to a multidisciplinary team of cancer providers across the full continuum of care and coordination of services, including prevention, early detection, staging evaluation, initial and subsequent treatment, palliative care, supportive therapies, long-term follow-up, rehabilitation, psycho-social services, and hospice. Oncology specialists are skilled in selecting treatment options and, in the case of terminal illnesses, are able to provide palliative care that improves quality of life.²

Patient Education on Treatment Options. Kentucky law requires distribution of information by physicians to all diagnosed breast cancer patients. The *Choices* booklet, which describes alternatives for the treatment of breast cancer, was distributed until late 1998 by the Community Health Branch of the Division of Adult and Child Health of KDPH. About 1200 copies of the booklet were distributed in 1997, at the request of doctors' offices or others. KDPH has adopted the National Cancer Institute booklet *Breast Cancer Treatment Options* for distribution in 1999.

Data Limitations. Data on treatment and survival following breast cancer diagnosis are available in the Kentucky Cancer Registry Annual Report. This is updated once a year after diagnosis, and therefore there is some lag time in getting current information. Likewise, death statistics in Kentucky lag a year behind due to the need to capture all death certificates and accurate causes of death.

With regard to capturing the total number of physicians who treat breast cancer, only board certified oncologic specialists have been counted. It is recognized that other physicians, not oncologic specialists, may be providing some cancer care.

At this point the Kentucky Cancer Registry does not have access to complete treatment data, particularly with regard to the medical oncology element in multiple modality therapy. Expansion of the Registry to include these additional data is planned.

² Statement on "Access to Quality Care" by the American Federation of Clinical Oncologic Societies, http://www.asco.org/prof/pp/html/f_gs.htm.

Quality of Life

Quality of Life for cancer patients is defined in terms of the physical side effects, functional status, psychological morbidity, and social interaction preceding and following diagnosis, treatment and habilitation.

Palliative Care gives temporary relief from the symptoms of a disease but does not actually cure the disease. This care includes pain management and symptom control, general concerns at the end of life. However, from the time of their diagnosis breast cancer patients also have available to them other services to improve quality of life, such as counseling, rehabilitation after extensive surgery to assist in their return to full functioning, and other assistance to help them return to their usual activities.

Support Groups/Education. Support groups may be led by professionals, such as those trained in social work, psychology, health education, or psychiatric nursing, or by trained lay persons, usually breast cancer survivors themselves. According to KCP, support groups for breast cancer patients exist in each KCP region, along with other services listed in the *Pathfinder*, a publication designed to meet the special needs of cancer patients and families by providing a resource guide to regional services. KCP, ACS, local hospitals, and other organizations throughout the state sponsor patient support groups offering information and discussions about physical, emotional, psychological, and/or spiritual issues, encouraging interaction among group members. Patients and families also receive information through the Cancer Information Service serving Kentucky as part of the National Cancer Institute's telephone information and outreach program. ACS conducts community cancer awareness programs and provides some direct support services to post-operative breast cancer patients through the Reach-to-Recovery programs. ACS also raises community awareness through co-sponsorship of *Relay for Life* activities throughout the Commonwealth. These community activities, which attract large participation by survivors, have an educational component through support group and medical equipment exhibits.

Hospice Care. Hospice is a program of multidisciplinary services for the terminal patient. Hospice services include pain management and palliative treatment for cancer symptom control provided by nurses and aides under medical supervision. In addition, social work services may be provided for patients who need financial assistance, housing, assistive devices or related services. Spiritual counseling is offered as well. Most patients can be cared for in their home, but some need placement in a nursing facility or the hospice unit in a hospital for a short period. Medicare and Medicaid pay for hospice care, as do most health insurance policies, but limit care to those who have six months or less to live, as certified by a physician, and who are past the ability to receive aggressive treatment.

Data were supplied by each Kentucky hospice on the number of unduplicated breast cancer patients for whom they provided care during 1997. Because of different reporting years used for hospice services for breast cancer patients (1997), and the most recent death data being from 1995, it was not possible to estimate the percentage of women dying of breast cancer in a given year who received hospice services. It is believed that nearly 100 percent of terminally ill breast cancer patients were served in regions with large hospices, and in regions with smaller hospices perhaps 30 percent were served. If the number of deaths remained steady over time, it could be estimated that about 70 percent of patients dying of breast cancer in a given year may have received hospice care.

Data Limitations. For this report it was not possible to obtain complete data on breast cancer patients' receipt of supportive care, such as physical and occupational therapy, counseling services, or the extent to which breast cancer patients are impacted in their work or usual activities and lifestyles. Such information for Kentucky patients is not available, except where the woman received care in an institution and a claim was filed. For these patients with a primary diagnosis of breast cancer, data would be available in the KDPH hospital claims data repository. At this time, data are not complete, especially for smaller hospitals, and are still being received for 1996, although data are more complete for 1995. While the Kentucky Cancer Registry obtains data on medical treatment for cancer, it does not obtain non-medical treatment information, such as palliative care, hospice care, or psychological or social services.

Hospice data are not reported in enough detail to the KDPH in their required annual report to determine breast cancer as the primary diagnosis. Therefore, data on hospice were obtained from a one-time survey of Kentucky hospices for the latest year, 1997. However, death certificate data to link these data lag behind by one or two years and the latest data on deaths were from 1995. These data do not allow for accurate estimates of the percent of breast cancer patients who have received hospice care. Neither do they capture persons dying from other causes secondary to breast cancer, because only a single cause of death is reported on death certificates. Data were not obtained from the hospices on the average reimbursement for a breast cancer patient from different payment sources.

Data on non-medical care for breast cancer, such as home health services, rehabilitation, psychosocial services, and others are generally not available. While hospital claims data are available from Medicare, Medicaid, and Kentucky hospital claims, the large volume of claims precluded obtaining data files and analyzing them for this report. In addition, the ambulatory claims data obtained by KDPH are not complete for all ambulatory facilities in the state at this time.

Summary

This profile has attempted to assess the educational, prevention, early detection, treatment and quality of life data for breast cancer patients in Kentucky, in response to the Governor's Charge. With over 2700 new patients being diagnosed each year, the data concerning services available to all patients are important. The financial costs of cancer are great both to the individual and to society as a whole. Insurance status and barriers to health care may affect the overall cost of treating cancer in this country. Many Kentucky families have members who experience difficulty or delay in obtaining care or do not receive needed health care services.

It is important that efforts be continued to define the data necessary to answer, on an annual basis, the questions asked of the Governor in his charge to the Breast Cancer Task Force.

Acknowledgments and Contacts

Information and data for this profile were collected and analyzed by the University of Kentucky Center for Health Services Management and Research. On behalf of the Task Force a special thanks is extended to the work of Joyce Beaulieu, Ph.D. and Jennifer E. Galland, MHA, for their work in meeting the Task Force requests. Appreciation is also extended to Mark Lancaster and Kjell Johnson, Research Assistants, for their construction of the maps found in the appendices.

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