Clinical Highlights from the National Cancer Data Base: 1996

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Introduction
The National Cancer Data Base (NCDB) is a community-oriented cancer management and outcomes data base for ongoing assessment of cancer patient care and a joint project of the Commission on Cancer of the American College of Surgeons and the American Cancer Society. The NCDB's bidirectional clinical information flow collects data on patient care and outcome from over 1,100 hospitals to NCDB Central and later disseminates findings and statistical comparisons back to the 1,100 hospitals, their physicians, and their community. This dissemination is facilitated by a triad consisting of (1) a 2,000-member oncologist network affiliated with hospital cancer committees, (2) American Cancer Society state and local unit staff, and (3) over 1,000 hospital-based cancer registrars.

The NCDB assesses patient care using both hospital cancer registry data collected annually1,2 and specifically targeted ad hoc hospital studies conducted periodically. These evaluations enable clinicians to appraise trends in specific treatments and survival in relation to stage and histologic types of malignancy. Further, they permit individual contributing hospitals to compare their results with state, regional, and national standards.

Sources of the Data
The methodology of the NCDB has been previously described.1,2 Case information is taken from five NCDB Calls for Data for cancers of all types (1989, 1991, 1992, 1993, 1994) and four special Patient Care Evaluation (PCE) studies, including colorectal cancer (1989), pancreatic cancer (1991), prostate cancer (1992), and cervical cancer (1992). In total, about 1,600 hospitals have voluntarily submitted data to one or more of these data requests.

National Cancer Data Base
Data are voluntarily submitted to the NCDB in computerized form by hospitals, central registries, and software
providers. This submission comprises a large convenience sample of cancer cases. These data are quite diverse. Forty-two percent of the cases were patients aged 70 years or older. The number of childhood cases (4,375) represents about 53 percent of all estimated childhood cancer cases in the United States. There were similar percentages of males (50.9 percent) and females (49.1 percent) among the reported cases.

Geographically, large numbers of cases were reported from each of six regions, ranging from a low of 34,186 cases reported from hospitals in the Mountain Region to 166,056 cases reported from the Midwest Region. With few exceptions, cases were widely reported from each state. Of the 50 states and the District of Columbia, five had reporting rates less than 30 percent of all expected cancers in the state, six had reporting rates of 30 to 39 percent, 12 had 40 to 49 percent, seven had 50 to 59 percent, and 21 had over 60 percent reporting. The five states with the lowest participation included Pennsylvania (26 percent), Iowa (18 percent), Kansas (17 percent), Nebraska (23 percent), and Alaska (19 percent). States with participation from 30 to 39 percent included Maine, New York, Mississippi, Montana, Utah, and California.

By ethnicity, 12.3 percent of the cases were not classified as non-Hispanic White, including 7.9 percent classified as African American; 2.9 percent, Hispanic; 1.4 percent, Asian; and 0.1 percent, American Indian. A large US population-based series of cases has reported a similar percentage of African Americans (8.2 percent). Even the ethnic group with the smallest percentage, American Indians, included 907 patients in this large national sample.

For analysis purposes, the cases were classified based on average family income of the zip code of residence. The cases were reported from hospitals with varying annual cancer caseloads, including 1.8 percent from hospitals with caseloads of less than 150 cases per year, 21.7 percent from hospitals with 150-499 cases, 41.3 percent from hospitals with 500-999 cases, 32.3 percent from hospitals with caseloads of 1,000 or more, and 2.9 percent from hospitals with unknown caseloads.

Most of the cases were reported from hospitals with Commission on Cancer approval status, including 3.8 percent from National Cancer Institute-designated cancer centers (comprehensive and clinical), 20.5 percent from teaching hospitals, 33.8 percent from community comprehensive cancer centers (300 or more cases per year), 29.6 percent from community cancer centers (less than 300 cases per year), and 0.5 percent from other approval categories. Cases reported from hospitals without approval status made up 11.7 percent of the total.

Most of the cases, 75.8 percent, were submitted by hospitals which reported that they both diagnosed and treated the cases; 3.0 percent of the cases were reported by hospitals that had diagnosed the cases with treatment received elsewhere, 20.2 percent of the cases were reported by hospitals that treated cases that had been diagnosed elsewhere, and 1.0 percent of the cases had an unknown hospital referral status.

**Patient Care Evaluation**

Data are voluntarily submitted to the PCE studies in paper questionnaire form by hospitals. Beginning in 1996, PCE data will be received from most hospitals in electronic format. These studies are usually specific to a particular type of cancer and designed to answer questions on patient demographics, diagnosis, treatment, staging, and outcomes in greater detail than is available from the NCDB longitudinal data. Feedback on the data collected for each study is returned to participating hospitals to help them develop their own patient care evaluations that are required for approval status with the Commission on Cancer. In addition, ag-
aggregate analyses are published in peer-reviewed journals.

Characteristics of hospitals participating in the PCE studies and demographics of submitted cases are similar to those in the NCDB. However, not all hospitals that participate in the NCDB participate in the PCE studies. A hospital may not have enough site-specific cases for the study period to submit or may have other reasons for not participating. In general, about 700 to 1,000 hospitals participate in each study. Since 1976, more than 29 studies have been conducted by the Commission on Cancer, with two more now being distributed to hospitals for patients diagnosed in 1996 with thyroid cancer or soft tissue sarcoma.

These NCDB and PCE data, from large numbers of patients, are presented as descriptive-survey data covering a number of variables of interest and are not intended to prove specifically targeted a priori hypotheses. Thus, a straightforward, stratified, and conservative assessment of the pattern of the data presented tempered by clinical judgement is most appropriate.

It should be recognized that the NCDB is a convenience sample of data voluntarily submitted by participating hospitals and central registries and is not necessarily representative of the nation as a whole. Most data are received from hospitals that have a computerized cancer registry, possibly introducing bias. Further, the data represent hospital-based care and do not cover care given patients outside the hospital setting. NCI-designated comprehensive cancer centers are underrepresented in the data.

These highlights summarize the principal findings presented in more detail in other reports, some of which have been published and others that are in press or submitted awaiting review. Collectively, these findings present a broad pattern of NCDB assessment of cancer patterns of care. In addition to the resulting journal publications, over 1,000 NCDB participating hospitals receive a customized summary of similar patterns of care and outcome at their facility compared with national norms, which are then used for quality assurance purposes.

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Pancreatic Cancer

- The most frequent symptom reported was abdominal pain (67 percent).
- The use of endoscopic retrograde cholangiopancreatography, abdominal computed tomography scans, preoperative carotid endarterectomy, and CA 19-9 for diagnostic workup is increasing.
- For AJCC-staged cases, 19.3 percent were stage I; 9.2 percent, stage II; 17.2 percent, stage III; and 54.5 percent, stage IV. The ratio of early disease (stage I) to advanced disease (stage IV) improved from 0.26 in 1985 to 0.36 in 1990.
- Older patients were less likely to receive cancer-directed surgery. Cancer-directed surgery rates were lowest for African Americans, patients from low-income neighborhoods, patients covered by Medicare/Medicaid, patients seen at institutions with lower pancreatic cancer caseloads, and patients seen at institutions without teaching affiliations.
- Operative mortality rates were higher for institutions with lower annual pancreatic cancer caseloads.
- Prognosis was poor. The two-year relative survival rate for pancreatic cancer patients diagnosed from 1983 to 1988 was 18 percent for stage I; 10 percent, stage II; 12 percent, stage III; and five percent, stage IV. The two-year survival rate for patients who were resected surgically was 35 percent.

Prostate Cancer

- The mean age at diagnosis for patients in both 1984 and 1990 was 72.3 years. Patients younger than 60 years constituted only 8.1 percent of the patients in 1984 and seven percent in 1990.
- The main methods of initial diagnosis are changing. From 1984 to 1990, there was increased diagnostic use of the prostate-specific antigen test (from 5.1 percent to 66.4 percent)10 Use of the prostatic acid phosphatase assay declined from 62.4 percent to 47 percent.
- The proportion of early-stage disease (stage 0, I, II) increased for all racial or ethnic groups combined from 57.3 percent in 1984 to 73.8 percent in 1993. The proportion of patients diagnosed with AJCC stage IV prostate cancer (metastatic disease) decreased from 25.3 percent in 1984 to 11.6 percent in 1993. The improvement in early detection was greater in whites than African Americans.
- Significant changes are occurring in treatment. Hormone therapy without radical prostatectomy declined from 24.4 percent in 1984 to 19.7 percent in 1990.
- The trend toward increased selection of curative treatment is continuing. In 1974, 9.2 percent of patients received radical prostatectomy as the primary therapy compared with 9.9 percent in 1986. By 1993, the proportion of the entire series treated by prostatectomy increased to 29.2 percent. Over the same interval, the proportion treated by radiation therapy increased from 26.7 percent to 30.1 percent, and the proportion of patients receiving only observation decreased from 41.8 percent in 1986 to 21.6 percent in 1993.
- In 1984, 28.7 percent of patents had a recurrence. Of these, 33.1 percent had a local recurrence, seven percent had a regional recurrence, 49.7 percent had distant recurrence, and 10.2 were classified with unknown recurrence type.
- African Americans had a lower five-year survival rate than whites, even when stratified for stage.
Lung Cancer

- There is a relatively even distribution of lung cancer cases across institutions from major designated cancer centers to teaching hospitals to smaller community hospitals.

- Of the 93,898 lung cancers reported, 15.5 percent were small cell lung cancer. Stage distribution for small cell lung cancer was 0.2 percent for stage 0; 8.7 percent, stage I; 3.8 percent, stage II; 30.4 percent, stage III; and 56.9 percent, stage IV. The ratio of advanced-stage disease (stages II, III, IV) to early-stage disease (stages O and I) was much higher (10.2) for all small cell lung cancers compared with the ratio (3.2) for non-small cell lung cancers.

- For non-small cell lung cancer, lobectomy (17.1 percent) was used more than pneumonectomy (4.0 percent). There was a higher incidence of resection in the NCI-designated cancer centers and teaching hospitals compared with smaller community hospitals. There was also a higher incidence of resection for tumors of lower histologic grade and for adenocarcinomas.

- Very few patients underwent surgical treatment for small cell lung cancer. Most patients received chemotherapy or combined chemotherapy and radiation therapy for most stage levels.

- Five-year relative survival for non-small cell lung cancer varied by stage with 42 percent for stage I; 22 percent, stage II; five percent, stage III; and three percent, stage IV. Five-year survival was 28 percent for grade 1 tumors; 19 percent, grade 2 tumors; 12 percent, grade 3 tumors; and 10 percent, grade 4 tumors. Five-year survival was uniformly poor for all age, sex, income, and ethnic groups (14 percent, all stages combined).

- Five-year survival for non-small cell lung cancer was analyzed by type of surgery by stage. For each stage, an advantage was reported for those who were selected for lobectomy/bilobectomy and partial wedge/segmental resection compared with those who received no cancer-directed surgery.

- These community-based data for non-small cell lung cancer are less favorable than some reports showing a five-year survival of T1N0M0 squamous cell carcinoma of about 80 percent, but are similar to those reported by the population-based SEER Program, which reported similar five-year relative-survival rates, including localized disease, 49.4 percent; regional, 16.0 percent; distant, 1.6 percent; unstaged, 8.3 percent; and all, 15.2 percent.¹³

Esophageal Cancer

- Between 1988 and 1993, there was an increase in the proportion of esophageal cancer cases that (1) originated in the lower third of the esophagus and (2) were adenocarcinomas.

- Most esophageal cancers are advanced stage, with 56.8 percent of the 1993 cases being American Joint Committee on Cancer (AJCC) stages III and IV. When compared with the stage distribution in 1988, a larger percentage of 1993 cases were advanced stage.

- There was a substantial increase in combined radiation therapy and chemotheraphy, primarily in stage II through IV cases, reflecting attempts to modify and broaden treatment to improve survival.

- Disease-specific survival rates are low for esophageal cancer cases, with only 50 percent of patients surviving one year and 20 percent surviving five years. Little difference was found in the five-year survival rate for the three anatomic sites.
Colorectal Cancer

- Interesting trends include (1) the elderly (aged 80 years and older) present with earlier stage disease than younger patients, (2) the NCI-recognized cancer centers have more patients with advanced disease than other types of hospitals, and (3) all ethnic groups have generally similar stages of disease at presentation, except for African Americans, who have a higher frequency of stage IV disease (25.4 percent versus 17.9 percent for all other groups).

- The shift of primary colon cancer to more proximal bowel locations continues with 54.7 percent of cancers in the cecum, ascending colon, and transverse colon in 1993 compared with 50.9 percent in 1988.

- For both colon and rectal cancer, AJCC staging is becoming more standardized as a marker of appropriate cancer diagnosis and treatment. Patients reported as unknown stage decreased for colon cancers from 79 percent in 1985 to nine percent in 1993. An apparent association between histologic grade and AJCC stage group of disease is reported. There is an association between stage of disease at diagnosis and location of the primary tumor. Sigmoid lesions were more likely to present as stage I (26 percent) than were primary lesions arising in the ascending colon or cecum (19 percent).

- Forty-three percent of patients with stage III colon cancer received adjuvant chemotherapy. Chemotherapy usage varied by region with most use in the Pacific Region (24 percent, all stages) and the lowest use in the Northeast (17 percent, all stages). Chemotherapy was also less likely to be used in older patients and at smaller hospitals.

- Both lower grade and distal site of primary tumor were associated with a more favorable outcome. For nonrandomized stage III patients, those receiving surgery only had a five-year relative survival of 44 percent compared with 49 percent for those receiving surgery and chemotherapy.

Ovarian Cancer

- Considerable improvement in the completeness of documented staging occurred between 1988 and 1993 (32 percent unknown stage in 1988 versus 11 percent in 1993).

- Most germ cell and borderline carcinomas occur in younger women and are more commonly diagnosed at an early age. Germ cell tumors account for only two percent of reported cases.

- A significant time trend in practice management is the increase in the percentage of women with stage I disease receiving surgery only as therapy. This likely reflects the increase in the percentage of women properly surgically staged allowing for conservative management.

- The relatively modest difference between five-year relative survival in patients having surgery only versus surgery and chemotherapy is of interest. This may reflect selection bias.
Breast Cancer

Ductal Carcinoma In Situ
- Modified radical mastectomy remains the most common surgical procedure despite the eligibility of many women for breast-conserving treatment.
- Radiation therapy is significantly underused in patients with partial mastectomy, especially when no nodes are removed.

Lobular Carcinoma
- Lobular carcinoma presents with similar features, including age distribution, anatomic subsite, diameter, and grade, as ductal carcinoma. In 1992-1993 data, stage distribution for lobular carcinoma was similar to that for ductal carcinoma.
- Breast preservation is less frequently selected for the management of lobular carcinoma than ductal carcinoma (31.1 percent versus 40.8 percent in 1992-1993), but use of this treatment approach has increased at a rate equivalent with ductal carcinoma.
- For all stages combined, the five-year relative-survival rate for lobular carcinoma was slightly higher than for ductal carcinoma for both patients treated with partial mastectomy (84 percent versus 80 percent) and patients treated with modified radical mastectomy (80 percent versus 77 percent).

Breast-Conserving Surgery and Survival
- The five-year relative-survival rate was reviewed in a large, nonrandomized cohort of 40,726 breast cancer patients seen in a wide range of US hospitals in 1985-1987 who were diagnosed with stage 0, I, and II disease. For premenopausal women treated with partial mastectomy and radiation therapy, survival was equivalent to those treated with modified radical mastectomy (stage 0, 93 percent versus 97 percent; stage I, 93 percent versus 90 percent; and stage II, 81 percent versus 78 percent). The same equivalence was reported for post-menopausal women (stage 0, 98 percent versus 90 percent; stage I, 91 percent versus 85 percent; and stage II, 83 percent versus 74 percent). These findings are consistent with clinical trials that have reported the efficacy of breast-conserving surgery for early-stage breast cancer.

Breast Cancer in the Young
- There was a higher percentage of high-grade tumors in young patients (younger than 35 years). Younger patients also had more advanced-stage disease.
- Younger women were more likely to have had breast-conserving therapy.
- Younger patients had poorer survival rates than patients aged 35 to 49 years.

Breast Cancer in the Elderly
- More than 20 percent of the women in this study were aged 75 and older at diagnosis. In the elderly, a lower percentage of cancers were detected by self-examination and a higher percentage by physician examination compared with younger patients. There was a lower incidence of needle localization biopsies in the elderly (11.5 percent) compared with the younger group (16.1 percent) and a lower incidence of mammographically detected lesions in elderly patients (50.6 percent in 1990) compared with younger patients (57.8 percent).
- In 1990, 20.6 percent of women aged 75 years and older received total or partial mastectomy without nodal dissection compared with 10.0 percent of younger patients. Of women who received partial mastectomy with lymph node dissection, 64.4 percent of the elderly also received radiation therapy compared with 78.2 percent of the younger women.
- At each stage of disease, older women had a slightly lower disease-specific survival rate than younger women.
Cervical Cancer

- The primary methods of diagnosis were cervical biopsy for 69.8 percent of patients, cervical conization for 9.3 percent, and both procedures for 11.8 percent of patients. The histopathologic diagnoses were squamous cell carcinoma (79.8 percent), adenocarcinoma (15.8 percent), and other (4.4 percent).

- The stage distribution for patients diagnosed in 1990 was IA, 15.9 percent; IB, 36.8 percent; IIA, 8.2 percent; IIB, 15.5 percent; IIIA, 2.5 percent; IIIB, 13.3 percent; IVA, 2.6 percent; and IVB, 5.2 percent.

- The use of surgery alone as treatment increased from 25.7 percent of patients in 1984 to 33.1 percent in 1990. Increased use of extended hysterectomy accounted for this change. The administration of some form of radiation therapy decreased from 66 percent in 1984 to 56.5 percent in 1990.

- Five-year disease-specific survival rates for patients diagnosed in 1984 were as follows: IA, 93.7 percent; IB, 80.0 percent; IIA, 67.2 percent; IIB, 64.7 percent; III, 37.9 percent; and IV, 11.3 percent.

Histologic Differences

- Fewer patients (50.5 percent) diagnosed with squamous cell carcinoma had stage I disease compared with adenocarcinoma (65.1 percent) or adenosquamous carcinoma (57.9 percent).

- Patients with squamous cell carcinoma had higher five-year disease-specific survival rates compared with patients with adenocarcinoma as follows: stage I, 84.1 percent versus 83.7 percent; stage II, 67.4 percent versus 56.8 percent; stage III, 39.8 percent versus 29.5 percent; and stage IV, 13.1 percent versus 5.3 percent.

Pregnancy

- The stage distribution for pregnant women diagnosed with cervical cancer was more favorable than women with cervical cancer who were not pregnant: stage I, 83 percent versus 53 percent; stage II, 10 percent versus 23 percent; stage III, three percent versus 16 percent; and stage IV, four percent versus eight percent. These findings may be related to the regularity of pregnancy-related obstetric examinations. Thirty-one percent of patients were diagnosed in the first trimester, 34 percent in the second, and 35 percent in the third.

- Surgery with curative intent was carried out in 70 percent of pregnant patients.

- Sixty of 161 patients (37 percent) carried the pregnancy to fetal maturity, 26 percent were delivered vaginally, and 74 percent by cesarian section.

- A progressive decrease in survival rate was observed for successive trimesters of diagnosis, with five-year disease-specific survival of 95 percent for patients diagnosed in the first trimester, 77 percent in the second semester, and 69 percent in the third trimester.