Clinical Highlights from the National Cancer Data Base, 1998

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Introduction

The National Cancer Data Base (NCDB) is a community-oriented cancer management and outcomes database that is a joint project of the Commission on Cancer of the American College of Surgeons and the American Cancer Society.1,2 The NCDB is best thought of not as a repository of data but rather as a mechanism for hospital, state, regional, and national cancer care surveillance.

Included in the NCDB are the database itself and a set of 16 teams of clinical experts organized according to disease site (for example, head and neck cancer, breast cancer, prostate cancer) who survey national care on a cancer-specific basis. The NCDB is closely partnered with members of a national physician network who serve as individual clinical liaisons to 2,200 cancer hospitals in the United States and their respective hospital cancer committees, influencing patient care.3,4

The NCDB assesses patient care using both traditional hospital cancer registry data collected annually (longitudinal data) and specifically targeted patient care evaluation studies conducted periodically on special subjects (cross-sectional data).5,6 These evaluations enable clinicians to appraise trends in specific treatments and survival in relation to stage and histologic type of malignancy. Further, the evaluations permit individual contributing hospitals to compare their results with state, regional, and national standards.

Patient care and outcome data from more than 1,600 hospitals are first sent by participating hospitals to NCDB Central, where they are subjected to edit checks and analyzed.7 The analyzed data are then sent back to the 1,600 hospitals, their physicians, and their communities with findings and statistical comparisons. This distribution is facilitated by the national physician network.
Sources of the Data

The methodology of the NCDB has been described previously. Case information for the highlights described in this article is based on six annual NCDB calls for data, including a recent patient care evaluation study. The data received by the NCDB include 232,577 cases from 501 hospitals for 1985 (24% of estimated cases in the United States), 238,157 cases from 496 hospitals for 1986 (26%), 322,117 cases from 740 hospitals for 1987 (38%), 461,544 cases from 935 hospitals for 1988 (47%), 468,805 cases from 841 hospitals for 1989 (46%), 408,372 cases from 839 hospitals for 1990 (39%), 519,293 cases from 978 hospitals for 1991 (46%), 647,950 cases from 1,144 hospitals for 1992 (56%), 608,289 cases from 996 hospitals for 1993 (53%), and 689,714 cases from 1,227 hospitals for 1994 (57%). Cumulatively totaling 4,596,818 cases. Since 1996, the data from patient care evaluation studies have been submitted with the NCDB data in computer-readable form.

Data were voluntarily submitted to the NCDB in computerized form by hospitals, central registries, and software providers and constituted a large hospital-based sample of cancer cases. These data were diverse, including all forms of cancer diagnosed in patients of both sexes, all ages (including childhood cancer), each of the 50 states, and all ethnic groups. The patients were drawn from all nationalities, native and migrant, and were treated by a wide range of different clinicians in all types of hospitals, rural and urban.

In the most current data year, 1994, 40% of the patients were 70 years of age or older. The number of childhood cases, 4,333, represents 53% of all estimated cases of childhood cancer in the United States. The percentages of male patients (48.6%) and female patients (51.4%) among the reported cases were similar.

Large numbers of cases were reported from each of six regions, ranging from 34,706 cases reported from hospitals in the Mountain Region to 164,835 cases reported from the Midwest Region. Cases were widely reported from each state. Regional representation closely followed the US census.

Sixteen percent of patients were classified other than non-Hispanic white, including 9% black, 5% Hispanic, 2% Asian, and 0.2% American Indian. Even the ethnic group with the smallest percentage, American Indians, included 6,565 patients in this large national sample, which was compiled from 1985 through 1994.

The 1994 cases were reported from hospitals with varying annual cancer caseloads, including 3% from those with fewer than 150 cases per year, 20% from hospitals with 150 to 499 cases, 41% from hospitals with 500 to 999 cases, 34% from hospitals with 1,000 or more cases, and 2% from hospitals in which the caseload is not known.

The cumulative NCDB data file includes large numbers of the most common cancers—for example 700,198 cases of breast cancer and 558,295 cases of prostate cancer. The large numbers allow a wealth of subset analysis without loss of sufficient sample size. In addition, rare tumors are present with some frequency—for example 2,918 cancers of the eye and 12,564 nasopharyngeal cancers. In the future, the NCDB should be a resource for patient care evaluation.
care evaluation of rare tumors or other subgroups of interest. The following highlights summarize the principal findings of NCDB and patient care evaluation articles published in 1997.

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American Joint Committee on Cancer Staging

- Overall, American Joint Committee on Cancer (AJCC) staging of appropriate sites increased from 78% of stageable cancers classified with AJCC staging in 1990 to 88% of such cancers classified in 1995. Increases occurred for every site except carcinomas of the skin, cancers of the extrahepatic bile ducts and urethra, melanoma of the eyelid, and retinoblastoma.

- The percentage of NCDB-participating hospitals staging all cases of cancer increased from 49% in 1990 to 61% in 1995, and the percentage not routinely staging decreased from 6% to 3%. Complete staging increased in all hospital categories except in for-profit hospitals. The trend toward complete staging was uneven among states and regions. This varied completeness at the hospital level by state, region, and type of hospital indicates that the adoption of routine staging is ongoing.

Brain Cancer (Meningioma)

- The overall 5-year survival rate reported was 69%, and it declined with age. When patients were grouped by histologic type of tumor, those with benign tumors had an overall 5-year survival rate of 70%, whereas the overall 5-year survival rates in patients with atypical and malignant meningiomas were 75% and 55%, respectively.

- Prognostic factors for benign tumor survival included age at diagnosis, tumor size, whether treated surgically, hospital type, and use of radiation therapy. The factors for malignant tumors were age at diagnosis, whether treated surgically, and radiation therapy. The 5-year rate for recurrence of symptoms was 18.2% for those with benign tumors and 27.5% for those with malignant tumors.
Breast Cancer: Ductal Carcinoma in Situ

From 1985 to 1993, the use of breast preservation therapy increased from 31% to 54%. The selection of treatment varied. Tumors with favorable sizes and grades were associated with increased rates of breast preservation and lower rates of axillary lymph node dissection and use of radiotherapy. Overall, only 45% of the patients who were treated with breast preservation received adjuvant radiotherapy.

During the period from 1985 to 1993, use of radiotherapy increased from 38% to 54%. Axillary lymph node dissection decreased from 52% in 1985 to 40% in 1993. Some experts have concluded that the rate of axillary lymph node dissection still remains inappropriately high and the rate of radiotherapy use remains low.

Breast-Preservation Surgery

Among 96,030 breast cancer patients reported with AJCC stages I and II, four treatment groups of interest were compared. One group, which included 8.9% of all patients, was treated with partial mastectomy, axillary lymph node dissection, and radiotherapy without systemic treatment. The second group, 4.0% of all patients, was treated with partial mastectomy, axillary lymph node dissection, and radiotherapy with systemic therapy. Modified radical mastectomy without systemic therapy was the treatment of the third group, which constituted 46.0% of all patients, and modified radical mastectomy with systemic therapy was the treatment of the fourth group, which constituted 19.1% of all patients. Within each stage, reported survival was the same or more favorable for patients managed with breast preservation compared with those treated with modified radical mastectomy. This comparability was observed in all subsets analyzed, including those defined by age at diagnosis, histologic grade, and tumor dimension.
Childhood Cancer

- The NCDB is a source of childhood cancer reports (42% of cases in the United States for the observation period reported, 1993) both from institutions that are members of the Pediatric Oncology Group (POG) and the Children’s Cancer Group (CCG) as well as nonmember institutions.\(^\text{24}\) Comparison was made between cases reported to the NCDB and those reported to a population-based series that did not collect benign brain tumor cases.\(^\text{25}\) The distribution of diagnostic groups reported to the NCDB was generally similar to that reported in the population-based series except for lymphomas and brain cancer. The distribution of diagnostic groups reported to the NCDB did not change over the 9-year reporting period (1985 to 1993). African American patients had the most different distribution of diagnostic groups compared with all other ethnic groups in the NCDB data.\(^\text{24}\)

- The survival of patients reported to the NCDB was similar to that of patients in the population-based series for many types of cancer, including Wilms’ tumor (89% in NCDB data versus 88% in population-based series), non-Hodgkin’s lymphoma (74% in NCDB versus 70%), soft tissue sarcomas (rhabdomyosarcomas 70% and sarcomas 79% in NCDB versus soft tissue sarcomas 71%), and neuroblastomas (58% in NCDB versus 57%). Grovas et al\(^\text{24}\) concluded that the number of brain tumors of benign and uncertain behavior being diagnosed was significant enough that they should be included in regional and national cancer registries that report data for clinical purposes. They further concluded that for reasons of representativeness and institutional coverage, the NCDB will be an important data base for pediatric cancers when national patterns are considered.

Colorectal Cancer

- The most common patterns of presentation of colorectal carcinoma were reviewed, and the status of clinical diagnostic methodology and the future potential of molecular diagnostic tests were summarized.\(^\text{26}\)
Hypopharyngeal Cancer

A national patient care evaluation survey was conducted to identify demographics and standards of care for treatment of hypopharyngeal squamous cell carcinoma. Little change was seen between the AJCC combined stage distribution reported in 1980 to 1985 and that reported in 1990 to 1992. In 1990 to 1992, 1,622 cases were diagnosed, including 2% stage 0, 9% stage I, 11% stage II, 20% stage III, and 57% stage IV. The percentage distribution of treatment modalities remained fairly stable between 1980 to 1985 and 1990 to 1992. In 1990 to 1992, patients were treated by surgery (11%), radiation (26%), chemotherapy (4%), surgery plus radiation (32%), surgery plus chemotherapy (1%), radiation plus chemotherapy (16%), and surgery plus radiation and chemotherapy (4%). Four percent were not treated. Overall, 5-year disease-specific survival was 33%. Stage-specific survival was 63% for patients with stage I disease, 58% for those with stage II, 42% for those with stage III, and 22% for those with stage IV. Survival was best for patients treated with surgery only (50%), similar with combined surgery and irradiation (48%), and worst with irradiation only (26%).

Renal Cancer

Three trends were reported. First, stage II disease is being diagnosed with increasing frequency. Second, an overall increase occurred in the frequency with which surgery alone is used as the primary treatment for patients with disease in stages I, II, and III but not for those with stage IV disease. Finally, partial nephrectomy rather than total nephrectomy is performed with increasing frequency as surgical treatment of patients with stage I renal carcinoma.
Laryngeal Cancer

- A slight increase occurred in stage IV disease between the periods 1980 to 1985 and 1990 to 1992. Use of radiation therapy also increased slightly. This indicates that early detection efforts have not been successful. The rise in radiation therapy may have reflected an increased use of nonsurgical treatment for early-stage patients and organ-sparing radiochemotherapy protocols for advanced-staged patients. Over time, differences in the management of this disease by site and stage became apparent, including a decrease in use of surgery alone from 25% in the period 1980 to 1985 to 19% in the period 1990 to 1992.

- Five-year survival rates showed a large difference among modified T and N groups within stages III and IV. The rates were 87.5% for patients with T1 to T2, 76.0% for those with T3 to T4, and 46.2% for those with N1 to N3. This suggests that ongoing refinement of the AJCC staging scheme may improve this cancer’s prognostic classification.

Non-Hodgkin’s Lymphoma

- High-grade cases of non-Hodgkin’s lymphoma (NHL) were more likely to be stage IV (41%) than were low- or intermediate-grade cases (35% and 33%, respectively). Patients with NHL arising from lymph node sites tended to present with more advanced disease (56% with stage III and IV disease) than did patients with NHL arising from extranodal sites and non–lymph node nodal sites (65% and 74%, respectively, with stage I or stage II disease).

- Approximately 67% of all patients underwent chemotherapy, and 25% underwent surgery or radiation. Five-year survival was 69% for patients with low-grade disease, 52% for those with intermediate-grade disease, and 46% for those with high-grade disease. When classified by stage, 5-year survival ranged from 74% for stage I to 43% for stage IV disease. Thus, this large sample of 91,306 patients confirmed the ability of the Working Formulation’s and AJCC staging groups to stratify patients usefully in predicting survival.
### Ovarian Cancer

- African American women with advanced ovarian cancer received less aggressive treatment than did white women and had poorer prognoses. African American women were more often diagnosed with stage IV disease than were white women, and African American women with advanced ovarian carcinoma were less often treated with combined surgery and chemotherapy than with chemotherapy alone. African American women had poorer survival rates than did white women regardless of income.

### Prostate Cancer

- Results showed that prostate cancer diagnosis and treatment vary by patient age, race, and regional origin. African American patients were more likely to have stage IV prostate cancer at diagnosis than were whites. Compared with younger men, men older than 75 had greater proportions of both the earliest stages of cancer and the more advanced stages. Overall, 25% of patients received no cancer-directed surgery, 12% were treated by hormones or endocrine surgery, 29% received radiation therapy, 28% underwent radical prostatectomy, and 7% were treated by other or combined modalities. Older patients are infrequently treated by radical prostatectomy. No treatment was most often reported from the Northeast Region. White patients were more likely to receive radical prostatectomy compared with African American patients (29% versus 22%) and less likely to elect no treatment.
Stomach Cancer

The analysis of patterns of care revealed unexplained variations in treatment and opportunities for improvement. Treatment of the elderly, infirm patient appears to be problematic. The proportion of patients treated by total gastrectomy increased, but proximal gastrectomy for proximal cancers remained popular. The proportion of patients who received postoperative adjuvant treatment declined. A substantial proportion of patients in the United States with early-stage disease receive no cancer-directed treatment. Stage-stratified 5-year relative survival was 71% for IA, 56% for IB, 37% for II, 18% for IIIA, 11% for IIIB, and 5% for IV.

Survival results suggested that elective splenectomy generally should be avoided in patients with stage II and III gastric cancer, underscoring the importance of surgical judgment for these patients.

Vulvar Cancer

The major diagnostic groups and the number of positive lymph nodes were confirmed to be prognostically important. Although earlier studies on vulvar disease found radiation therapy beneficial for patients with more than one positive lymph node, radiation therapy was not predictive of survival for patients in this report. Radiation therapy was given equally to patients in all lymph node–positive categories (1, 2 or 3, and 4 or more positive nodes) with little change between the periods 1988 to 1989 and 1993 to 1994.
NCDB Data Completeness and Comparability

- Surveillance, Epidemiology and End Results (SEER) program data from 1992 on breast, colorectal, lung, and prostate cancers were compared with NCDB data. The 1992 NCDB data, in aggregate, described patient and disease treatment characteristics and patterns that differed only marginally from those described in the SEER data from the same year.

- Similar levels of data completeness were observed. The NCDB data contained less complete information about the Hispanic ethnicity of patients. Tumor grade data tended to be incomplete in both series. For example, the percentage of grade unknown for four cancers was breast: SEER 45%, NCDB 41%; colorectal cancer: SEER 22%, NCDB 19%; lung: SEER 41%, NCDB 36%; and prostate: SEER 10%, NCDB 10%. Stage information about lung and prostate cancer was more often missing in SEER data. Tumor laterality, anatomic site, tumor grade, and types of surgical treatment were similar in the NCDB and SEER data. Radical mastectomy was performed in 49.4% of SEER patients with breast cancer compared with 49% of NCDB patients with breast cancer. Cancer-directed surgery was observed more often among SEER patients with prostate cancer (49%) than among NCDB patients (43%). The NCDB data also showed greater use of radiation therapy than the SEER data for the three types of cancer reviewed, including 4% greater for colorectal cancer, 12% greater for lung cancer, and 8% greater for prostate cancer.

- Regional representation of the NCDB was broader than that of SEER. In a comparison with US adult populations in six US regions, the NCDB cases closely mimicked the US population (Northeast: US population 20.2%, NCDB 19.0%, SEER 13.6%; Southeast: US 17.6%, NCDB 17.7%, SEER 9.5%; Midwest: US 23.9%, NCDB 25.6%, SEER 27.9%; South: US 16.8%, NCDB 15.7%, SEER 0%; Mountain: US 5.6%, NCDB 5.3%, SEER 14.0%; Pacific: US 15.9%, NCDB 16.6%, SEER 35.1%) (Figure).
Quality Management

- The results and implications of a field reabstracting study of NCDB data from the Midwest Region were presented. The vast majority of reabstracted codes were consistent with the codes submitted. The inconsistencies were not clustered in a few records but were found across the board. Nearly half (47%) of the reabstracted records had a discrepancy for at least one audit term. Less than 90% agreement was found on eight of the 29 items reabstracted: cT, clinical stage group, cN, cM, day of first treatment, surgery, pT, pathologic stage group, and tumor size.
- Two underlying problems were noted during the assessment of the data: lack of documentation and software idiosyncrasies. The implications included the following: for the NCDB, data edit reports will continue to improve coding consistency. For the hospital registry staff, emphasis should be placed on review, and for software providers and standard setters, continued vigilance in the use of standardized coding is important.