USE OF THE SEER CANCER REGISTRY FOR TECHNOLOGY ASSESSMENT

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Abstract

The Surveillance, Epidemiology, and End Results (SEER) cancer registry contributed to technology assessment by providing population-based samples for detailed case-control studies, by serving as the control group in comparisons with various experimental groups, by allowing an assessment of selection bias in clinical trials, and by facilitating evaluations of classification and coding systems.

In this article, we consider the Surveillance, Epidemiology, and End Results (SEER) registry of the National Cancer Institute (NCI) to ask what role this registry, originally established to monitor trends in the incidence and survival of cancer, has played in technology assessment as seen in the medical literature.

BACKGROUND ON SEER

The NCI initiated the SEER program in 1973 by building on the experience of two earlier NCI programs: the End Results Program and the National Cancer Survey (17). The End Results Program was primarily a hospital-based cancer registry established in 1950, providing demographic, diagnostic, and survival data on persons diagnosed with cancer in Connecticut, parts of California, Charity Hospital in New Orleans, and the University of Iowa Hospital. The degree of representativeness of the survival data was unknown. Prior to 1973, three National Cancer Surveys had been conducted to provide national estimates of the incidence of cancer (17).

The SEER program is a population-based registry that provides cancer incidence and survival data on a portion of the U.S. population. The program now includes five entire states — Connecticut, Iowa, New Mexico, Utah, and Hawaii — and four metropolitan areas — Atlanta, Detroit, San Francisco–Oakland, and Seattle. Together, these nine areas contain about 10% of the U.S. population.
SEER contracts with local nonprofit organizations to collect the data. Coding teams record all neoplasms according to the *Stage of Disease Coding Manual* from medical records in hospitals where residents of the target area are diagnosed and treated. The abstracters also code the first course of cancer-related treatment using broad classifications such as surgery or radiotherapy (25;36). SEER staff continue to develop methods to provide more specific information on courses of treatment. For example, beginning in the early 1980s, SEER began utilizing Expanded Extent of Disease (EED) Codes for diagnostic data and incorporated more detail on the types of surgical intervention in the data recorded on therapy.

Contractors maintain files of active follow-up on all living patients. This responsibility includes matching the entire active file at least once a year against a complete file of deaths in the registry area. The contractor then submits to NCI data on all cases diagnosed since 1973 with follow-up information through the latest possible date, including the last date that the patient was known to be alive or to have died (25;36). For purposes of computing mortality rates, SEER staff obtain data on deaths from all causes in the United States annually from the National Center for Health Statistics (NCHS). To compute incidence rates for cancer of all sites, the program obtains population estimates by age, sex, and race for each SEER area from the U.S. Census Bureau. The SEER program, which is now within the Division of Cancer Prevention and Control of NCI, emphasizes the use of SEER data for assessing the effectiveness of diffusion of diagnostic and therapeutic technologies for cancer.

METHODS

We searched the National Library of Medicine’s computerized bibliographic data base, MEDLINE, from 1973 to 1989 and captured 119 articles with either the word SEER or the words surveillance, epidemiology, and end in the title or abstract. The word results is so common a word that it cannot be used as a search word. Since we were mainly concerned with the use of the SEER registry in its entirety, we searched only on SEER and not on its nine constituent state and metropolitan registries. We did not make an effort to find articles that use only one of the constituent registries. We note that the Connecticut Tumor Registry (CTR) is covered in a companion article to this one (33). Our search also produced several articles that dealt with only parts of SEER; of these, we included four in our analysis (10;22;28;29).

Two readers reviewed the abstracts and judged 30 to have a possible connection to technology assessment. The other articles were mainly epidemiological studies of trends in incidence of cancer and survival or studies of risk factors such as ethnicity or smoking. One article dealt with a seer who could predict or “see” the future.

Each of the 30 articles selected for review was read by two people. We discovered varying amounts of information related to technology assessment in these articles. Collectively, we divided these articles into three groups: (a) 7 articles that used SEER directly for technology assessment (10;15;22;24;28;29;32), (b) 9 articles that used SEER data indirectly for technology assessment (as a control group for another study) (3;4;7;12;13;14;21;26;27), and (c) 14 articles unrelated or only marginally related to technology assessment (5;6;8;9;11;16;18;19;20;23;30;31;34;35). Readers filled out the protocol described by Antczak-Bouckoms et al. (1) for group (a) articles. For group (b), readers filled out only the sections on description of the technology and on conclusions, and for group (c), they wrote brief summaries of the articles. We included only groups (a) and (b) in our evaluation. These 16 articles appear with an asterisk in the reference list.

As shown in Table 1, we note that the annual number of SEER articles that we...
Table 1. SEER Articles Related to Technology Assessment

<table>
<thead>
<tr>
<th>Year of publication</th>
<th>Total no. SEER articles found</th>
<th>No. of technology assessments</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤1979</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1980</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>1981</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>1982</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>1983</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>1984</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>1985</td>
<td>16</td>
<td>3</td>
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<tr>
<td>1986</td>
<td>19</td>
<td>2</td>
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<tr>
<td>1987</td>
<td>19</td>
<td>4</td>
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<tr>
<td>1988</td>
<td>22</td>
<td>4</td>
</tr>
<tr>
<td>1989a</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>119</td>
<td>16</td>
</tr>
</tbody>
</table>

a The search was conducted before MEDLINE was complete for 1989.

found continues to rise slowly, as does the number of articles related to technology assessment.

Several articles attempted global assessments of cancer programs in specialized areas (11;23;30). Their investigators reviewed changes in SEER survival rates over periods of 10–20 years, looking for improvements in survival rates. Bailar and Smith (2) and others have criticized this approach to evaluating the nation’s program on cancer as being subject to important biases. For example, recent improvements in diagnostic technologies allow physicians to make earlier and more detailed diagnoses of cancer. The same tumor diagnosed at an intermediate stage now because of the current technological ability to detect subtle extensions might have been described as an “early”-stage tumor if diagnosed a number of years ago. Similarly, tumors currently diagnosed as early stage might not even have been detected formerly and are likely to have better survival rates than tumors diagnosed as early stage in the past. The improvement in technology to detect cancerous tumors and their spread allows more sensitive diagnoses of the disease. More recent classifications of stage of disease may show a higher survival rate than older, similar classifications because of the ability to define the stage of disease more accurately. Bailar and Smith (2) indicate that bias because of changes in diagnostic practices can be avoided by comparing population-based, age-adjusted death rates rather than survival rates for diagnosed cases.

RESULTS

We grouped the 16 articles into three major categories: population-based samples, classification and coding systems, and population-based control groups (see Appendix).

Three articles used SEER to identify a population-based sample for a more detailed study (22;28;29). In the article by Moss et al. (22), investigators interviewed men diagnosed with germ-cell carcinoma of the testes identified in the SEER registry for the San Francisco–Oakland Standard Metropolitan Statistical Area. They asked all available living mothers about hormone use, mostly diethylstilbestrol (DES), during pregnancy. The investigators obtained case controls by requesting names of peers from the sample males. The results of the analysis showed no significant association between
The investigators evaluated prenatal hormone use for possible carcinogenic side effects. They did not assess the original purpose of the treatment, preventing miscarriage in the mothers.

The other two studies evaluated the effectiveness of patient-initiated intervention. Smith et al. (28;29) evaluated self-detection of endometrial cancer and breast self-examination (BSE). Investigators interviewed patients and controls on their frequency of BSE. While BSE patients who performed BSE two or more times a year were more likely to find the breast tumor themselves than were non-BSE patients, there was no significant improvement in tumor size, the number of lymph nodes involved, or the stage of disease at diagnosis. We note that the technology evaluated here was a set of activities.

We found four articles (10;15;24;32) that used SEER data to evaluate classification and coding systems for various cancers. Henson (15) used 211,604 SEER cases that coded histology from 1981–1985 to show that histological grade has prognostic value for survival. Dick et al. (10) compared SEER abstracts with abstracts obtained from the Factors Affecting Rural Males (FARM) registry on the same 298 cases of non-Hodgkin lymphoma (NHL) in the Iowa cancer registry. Dick et al. (10) found significant nonconcordance in the form of poor agreement in the pathological diagnosis of subtypes of NHL.

Information technologies such as classification or staging systems are often critical to measuring improvement resulting from a medical intervention. The evaluation of their reliability and utility constitute an important underpinning for medical technology assessment.

The largest category contained nine articles that used SEER incidence and survival data as a control group for comparison with specific study groups without considering individual case data. For example, four articles evaluated the carcinogenic side effects of technologies (3;12;13;14). An article by Beard et al. (3) measured the occurrence of cancer associated with exposure to metronidazole, a drug that was used to treat vaginal trichomoniasis in 771 women during the period 1960–1969. The investigators compared the observed incidence of cancer in the group with the expected incidence of cancer. They obtained the expected number of cases by applying age-specific incidence rates derived from SEER. The other three articles on carcinogenic side effects assessed the risk of leukemia from adjuvant chemotherapy for cancer (12) and the risk of breast cancer from the postmenopausal use of hormones (13;14).

One article evaluated selection bias in large clinical trials. Cohen and Bartolucci (4) evaluated the impact of age on response to treatment, survival, and toxicity of chemotherapy for multiple myeloma. As part of the assessment, the investigators compared the age distribution of patients in the trial with incidence figures obtained from SEER and found underrepresentation of the oldest patients. SEER was used to determine the representativeness of the trial cohort and not to assess the age-related effectiveness or toxicity of the treatment regimen. Thus, SEER is used to determine how far the trial results can be generalized.

Three articles dealt with the effectiveness of special demonstration programs in comparison to SEER as a population standard (7;21;27). Ryan et al. (26) used SEER similarly as a population-based comparison for a new procedure at a specific site. They compared radical surgery for osteogenic sarcoma of the mandible with conventional therapy and found that it yielded significantly better survival than found in the SEER control population, although the numbers of cases are very small.
DISCUSSION

In Methods, we remarked that changes in diagnostic precision could affect comparability of patients registered in different years. Changes in therapies, both at diagnosis and during follow-up years, may also make it difficult to compare people treated in different years. Furthermore, changes in environmental exposure to carcinogenic factors may also vary over time. These considerations need to be kept in mind for registries like SEER that accrue and follow people over an extended period.

We noted in the background section on SEER that abstractors coded information on the first course of treatment by specifying broad categories such as surgery or chemotherapy, with additional detail beginning in 1983. Therefore, it is not surprising that SEER data typically is not detailed enough to be used alone in technology assessment. In our sample of SEER articles, we found no study that used SEER data alone for technology assessment. Typically, SEER has been used for technology assessment in conjunction with other sets of data.

SEER provides a basic set of clinical data on cancer in the entire populations of five states and four metropolitan areas. For this reason, the SEER data were found to play useful roles in providing population-based samples for more detailed case-control studies, in serving as a population-based control for comparison with various experimental groups, in assessing selection bias in trial groups, and in evaluating classifications and coding systems.

REFERENCES


### APPENDIX

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<tr>
<th>Categories of Technology Assessment</th>
<th>Technology</th>
<th>Article</th>
<th>Technology Conclusion</th>
<th>Data Collection Process for Multicenter, Population-Based Case-Control Study of Risk Factors in Breast, Ovarian, and Endometrial Cancers</th>
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<tr>
<td>Population-based Samples for Case Studies</td>
<td>Paternal self-detection of endometrial cancer</td>
<td>Smith and Anderson (28)</td>
<td>No significant effect on incidence of testicular cancer in sons</td>
<td>Factors detected by patients not distinguished as guiding earlier detection</td>
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<td>Population-based Samples for Case Studies</td>
<td>Carcinogenic side effects of prenatal hormone use</td>
<td>Beard et al. (3)</td>
<td>No significant increase in cancer related morbidity or mortality</td>
<td>No increased risk of breast cancer</td>
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<td>Classification and Coding Systems</td>
<td>Hodgkin's lymphoma in FARM vs. coding in SEER</td>
<td>Dick et al. (10)</td>
<td>No significant effect on the incidence of testicular cancer in sons</td>
<td>No increased risk of breast cancer</td>
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<td>Henson (15)</td>
<td>No significant increase in cancer related morbidity or mortality</td>
<td>No increased risk of breast cancer</td>
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<td>Classification and Coding Systems</td>
<td>Data collection process for multicenter, population-based case-control study of risk factors</td>
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<td>No increased risk of breast cancer</td>
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<td>Carcinogenic side effects of prenatal hormone use</td>
<td>Postmenopausal estrogen-progestogen use</td>
<td>Gambrell (13)</td>
<td>No significant increase in cancer related morbidity or mortality</td>
<td>No increased risk of breast cancer</td>
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<td>Carcinogenic side effects of prenatal hormone use</td>
<td>Postmenopausal estrogen-progestogen use</td>
<td>Fisher et al. (12)</td>
<td>No significant increase in cancer related morbidity or mortality</td>
<td>No increased risk of breast cancer</td>
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*Note: The table continues on the next page.*
### APPENDIX (continued)

<table>
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<th>Article</th>
<th>Technology</th>
<th>$n$</th>
<th>Conclusion</th>
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<tr>
<td>Gambrell et al. (14)</td>
<td>Postmenopausal hormone use</td>
<td>256</td>
<td>No increased risk of breast cancer from estrogen; progestogen lowers risk</td>
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<td>Chemotherapy for multiple myeloma: survival and toxicity related to age</td>
<td>374</td>
<td>Age distribution in trial shows underrepresentation of oldest group compared to SEER; hemotoxicity and survival of older patients is comparable to that of younger patients</td>
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<td>Davis et al. (7)</td>
<td>Hodgkin's disease management in Comprehensive Cancer Centers (CCCs)</td>
<td>2,278</td>
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<td>4,240</td>
<td>Better survival due to earlier detection as compared to SEER</td>
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<td>BCDDP</td>
<td>55,053</td>
<td>Higher incidence as compared to SEER, but lower case fatality for cases detected at screening</td>
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<td>16</td>
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</table>

*Abbreviations: FARM, factors affecting rural males; WF, working formulation.*