The Sentinel

The Newsletter for the Association of North Carolina Cancer Registrars
Fall 2008

Message from ANCCR President
Deborah Carrethers, CTR

Dear ANCCR members,

Thank you for electing me to serve as President. It is a pleasure to be able to work with each and every one of you this coming year. I have held several offices and been on different committees for ANCCR; I would never have thought that one day I would be president. This is such an honor and privilege for me.

This year's meeting was held in Winston Salem at the Brookstown Inn. First of all I would like to thank Forsyth Medical Center and WFUBMC for doing such a great job. The speakers were very informative and the literature given was helpful. Next year's meeting will be in Asheville at the end of August. The program committee is already hard at work making this another great meeting.

I know that this fall has been busy for everyone with October being Breast Cancer Awareness month and November being Lung Cancer awareness month. On November 15, 2008 the Triad held their first Lung walk called Free to Breathe and this was with the NC Lung Cancer Partnership. It was estimated that we had 811 walkers and runners. The total raised was $70,000. Raleigh NC also held a lung walk a week earlier.

Since it is now December, I know you are all working hard on your 2008 cases. If you have any questions or know about any changes that might help registrars, please contact Carol Burke (carol.burke@pardeehospital.org) so that she can include them in future issues of the Sentinel.

Once again I am excited about this coming year and I look forward serving ANCCR. I am always available to answer questions or talk. Please contact me at dgcarrethers@novanthealth.org or (336)718-8463.

May each of you have a happy holiday and a healthy and prosperous New Year.

Deborah Carrethers, CTR
President, ANCCR

NC Central Cancer Registry
Melissa Pearson, CTR

NPCR 2004 CENTRAL NERVOUS SYSTEM QUALITY CONTROL STUDY REPORT

(The following is a summary of the report distributed to Central Cancer Registries in December 2007)

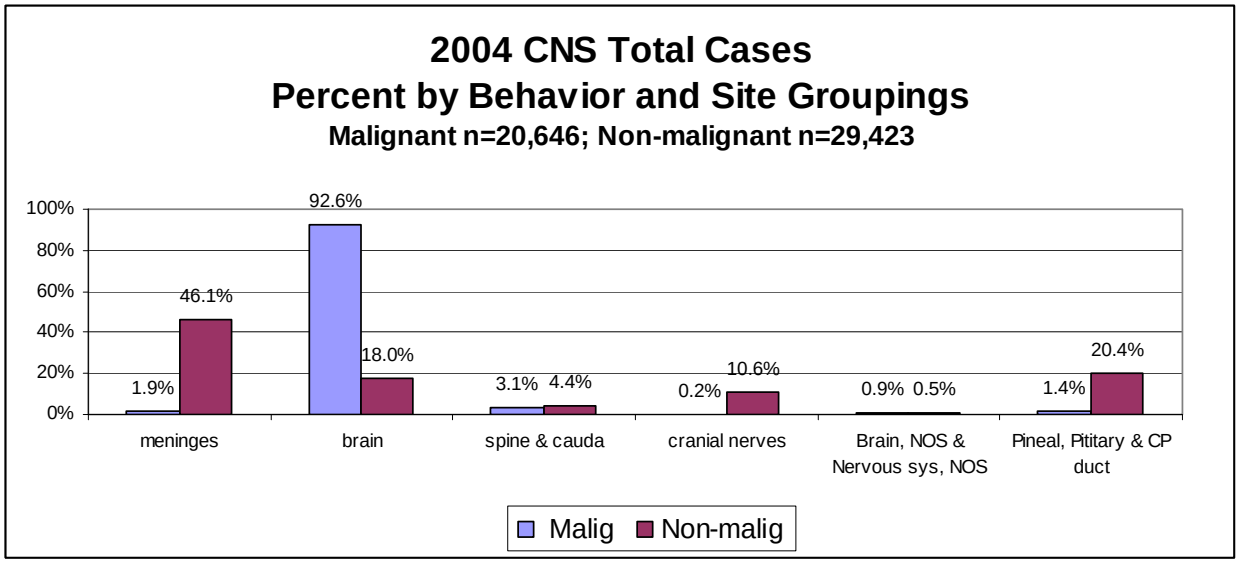
In 2007, the National Program of Cancer Registries (NPCR) conducted a quality assurance audit of 2004 Central Nervous System (CNS) data because 2004 was the first year of required reporting for non-malignant CNS data. In addition, no quality control activities sponsored by NPCR in the past have included CNS data. Therefore, it was decided to review both malignant and non-malignant cases in this study.

This study reviewed 50,069 CNS reports. CNS tumors represent 3.14% of the total 1,593,909 cases submitted to NPCR for 2004. The number of cases with errors also represents a very small portion of CNS cases. Even though these cases represent a very small portion of the NPCR and central cancer registry (CCR) data overall, NPCR has the largest number of CNS cases in the US. This data will also be shared with the Central Brain Tumor Registry of the United States (CBTRUS), which serves as a resource for gathering and disseminating current epidemiological data on all primary brain tumors. Their data are available to assist in research projects that intend to describe incidence of brain tumor cases, to evaluate diagnosis and treatment, and to conduct etiologic studies.

This review identified the need for additional training regarding recording primary site and histology for both malignant and non-malignant CNS tumors. As a result of this review, NPCR has developed some CNS Coding Guidelines which are provided with this report. Results of this study will be correlated with coding guidelines.

Figure 1 shows the distribution of cases by behavior and site. Each category is calculated on the total number of cases for that behavior. For example, 46% of the non-malignant tumors were coded to meninges, and 93% of the malignant tumors were coded to brain.

Fig. 1.



NPCR Coding Guidelines for CNS tumors (October 2007)

NPCR has developed coding guidelines for CNS tumors. These guidelines have been reviewed by CBTRUS, Edward R. Laws, MD, Professor and Vice-Chair, Department of Neurosurgery, Stanford University Medical Center, Advanced Medicine Center, and Roger E. McLendon, MD, Chief, Neuropathology and Surgical Pathology, Director Anatomic Pathology Services, Division of Neuropathology, Duke Medical Center.

- Always use the **behavior code** listed in the ICD-O-3 unless otherwise directed by a pathologist.

  Examples of miscoded behavior: benign meningiomas (9531/0, 9532/0, 9533/0) coded as malignant. Gliomatosis cerebri (9381/3) and Ependymoma (9391/3) were coded as non-malignant.

- **Meningiomas** (9530–9539)
  - Always coded to meninges (C70.-) unless specifically directed otherwise by a pathologist.
  - Intraparenchymal meningiomas are **exceedingly rare**.
  - Meningioma can also occur as a tumor of the choroid plexus (C71.5 Brain) in **rare cases**.

  Examples of miscoded sites: only 23% of non-malignant meningiomas were coded to meninges with 72% being coded to brain. Of the total number of meningiomas reported, only 28% were coded to meninges. The other 72% were coded to other CNS sites.

- **Germ cell tumors** (9060-9091)
  - Those originating intracranially are usually located in the **pineal gland (C75.3)**, **suprasellar region** (**C71.9** Brain, NOS)**,** and **posterior 3rd ventricle** (**C71.5)**.
    - Code to site of origin.
  - A **teratoma** (M908-) is always a germ cell tumor. It may be malignant or non-malignant. The only <u>non-malignant</u> teratomas that are reportable are those occurring intracranially.

- **Craniopharyngiomas** (9350/1)
  - All craniopharyngiomas are non-malignant.
  - Very few of these tumors actually arise in the craniopharyngeal duct. Most are either suprasellar (**C71.9** Brain, NOS)**,** or in the 3rd ventricle (**C71.5)**.

Examples of miscoded sites: 12% were coded to other areas of the brain.

NPCR Coding Guidelines for CNS tumors (October 2007)

- **Chordomas** (9370-9372)
  - Chordomas are malignant tumors so ALL chordomas are reportable.
  - These tumors usually start in the bone at the back of the skull (**C41.0** bones of skull) or at the lower end of the spinal column (**C41.2** vertebral column). 35% occur at the base of the skull.
  - Intracranially, the tumors occur at the clivus (**C41.0** bones of skull), and occasionally in the parasellar and sellar area (**C71.9** Brain, NOS).
  - All chordomas should be **coded to the bone of origin** unless otherwise directed by a pathologist.

- **Choroid plexus tumors** (9390)
  - Located in the ventricular system
  - Code to ventricle (**C71.5)** unless otherwise directed by a pathologist.

Examples of miscoded sites: 4% of the malignant and 21% of the nonmalignant choroid plexus tumors were coded to other parts of the brain.

- **Nerve Sheath Tumors** (9540-9571)
  - Malignant: all malignant tumors are reportable. Always code to nerve of origin (**C47.-** or (**C72.-**).
  - Nonmalignant: reportable <u>for intracranial segment of cranial nerves only</u>. Always code to the nerve of origin, (**C72.2, .3, .4, & .5)**

Examples of miscoded sites: 31% of the non-malignant nerve sheath tumors and 54% of malignant nerve sheath tumors were coded to sites other than the nerve with a wide variation across CNS sites.

“Downtime”

This is a new section of The Sentinel where our members can share what they do in their downtime. This can be crafts, music, gardening, or any kind of activity or hobby that you would like to tell us about. Just a short paragraph telling us about your project and a picture or two is all that we need.

Our first downtime article is from Cher Stone-Bustle at Iredell Memorial in Statesville.

This is what I do in my spare time. This is my "fence" I gather the rocks lying around in the pasture adjoining our property and use them to build my wall. This is a "dry wall" no mortar to speak of and is fitted together like a puzzle. This is my hobby, I do by myself. Well my husband and father in law drive the tractor with the trailer that has my rocks and of course they help pick up any thing that is to heavy for me to get by myself but the actual building of the wall is all me. I can do about 20 feet per load and I have been working on since March of 2008.

"THE BOY NAMED SUE AND OTHER EMBARRASSING MISCODES"

VALIDATING YOUR CASES PRIOR TO TRANSMITTING TO THE NC-CCR OR NCDB AND PRIOR TO PREPARING YOUR CANCER REGISTRY ANNUAL REPORT

BY SANDY OVERTON, BS, CTR
MANAGER – QUALITY CONTROL & FIELD SERVICES
NORTH CAROLINA CENTRAL CANCER REGISTRY

Validating your cases prior to transmitting them to the North Carolina Central Cancer Registry (CCR) or the National Cancer Database (NCDB) and prior to preparing your annual report insures accurate, meaningful data and will identify errors missed by registry software edit programs. It will also prevent those embarrassing miscodes like females named Ralph and males named Sue.

The following are some simple tips to validating your data prior to transmitting to the CCR/NCDB or generating statistics for the annual report. For this process, query the database using a range of 1-1 to 12-31 in "Date of first contact." Do not specify complete, incomplete, suspense status, or analytic vs non-analytic. You want to review all cases first seen for the given year.

Run the following ten reports prior to transmitting to the CCR/NCDB or generating the Cancer Registry Annual Report year-end statistics.

1. **Sort by Sex and First Name**
   Create an *ad hoc* report that displays the medical record number, sex, first name, age, race, social security number, and primary site.
   Run the report and sort by sex and then first name.
   This will allow you to quickly peruse the list and see if there are any "Jane's" or "Ellen's" in the male group or any "Jack's" or "Allen's" in the female group.
   If you find a suspicious entry, look up the patient in the hospital data base to see if the patient is male or female. You might also investigate the spouse's first name to determine the sex of the patient, especially if the patient's name is unusual or androgynous like Dale or Chris. If the patient has a suffix of Jr or Sr, then code Male; if maiden name is completed then code female. Occupation may also provide information on gender (housewife for example).
2. **Sort by Age at Diagnosis**
   Sort the same file by age at diagnosis.
   Look at both ends of the list, to see if there is anything out of the ordinary. Compare very young individuals with the assigned primary site. Pediatric cases have very limited acceptable site/histology codes. Look at very old individuals to evaluate if the age is reasonable for the site. Anyone over 100 should be checked and a note written in the PE or Remarks Text field to confirm the age. Investigate any outliers and correct the database if necessary. Document in text fields any out-of-the-ordinary ages.
3. **Sort by Race**
   Sort the same file by race. Look for an excess number of "unknowns." Review each of these cases to see if you are able to assign a race code. If you have access to the Radiation Oncology record, often a photograph of the patient is included in the chart. This can help in cases of conflicting information. Document in the text field if Race is unknown or not stated in the medical record.
   The CCR collects specific information on Native American Indian tribe, so if you code Race as 03, be sure to complete the American Indian Tribe field.
4. **Sort by Social Security Number**

Are there any 9's for unknown SSN? If so, make an extra effort to find the SSN as it is very important when linking with other abstracts in the Eureka database and other national databases. If you have access to the Radiation Oncology or Medical Oncology chart, you may find SSN in these documents even though it is missing in the hospital database.

Create another *ad hoc* report that prints the medical record number, primary site, histology/behavior, grade, laterality, and class of case.

5. **Sort by Class of Case**
   Are there any 9's or blanks? Correct these if you find any or document in PE or Remarks Text field that Class of Case is Unknown. Very few cases will be coded 9. Examine the file to see if there are any cases still in "Suspense" or "Incomplete" status that need to be completed for the submission year.
6. **Sort by Primary Site Code**
   Compare the primary site to the histology. Look especially at Unknown Primary cases – can these be assigned a more specific code? For example, a malignant melanoma case that is coded as an Unknown Primary can be coded to Skin, NOS. Sarcomas can be coded to Connective and Soft Tissue, NOS. Meningiomas should be coded to the primary site code Meninges.
7. **Sort by Histology Code**
   Compare the histology to the primary site. Certain histologies are associated with certain anatomic sites. For example the primary site of origin of a squamous cell carcinoma of the "Kidney" is more likely to be the Renal Pelvis. GE junction tumors can be difficult to determine if esophageal or gastric in origin – histology (adenocarcinoma vs. squamous cell carcinoma) may assist in assigning the primary site code.
8. **Sort by Laterality**
   Are there any 9's? There should be very few "unknown if left or right." Review cases coded with 9, to determine if there is enough information to assign laterality. If impossible to assign a laterality code, document in the text field. Use code 3 if you know only one side is involved but it is unclear whether it is right or left.

Create another *ad hoc* report that prints the medical record number, city, county, state, and class of case.

9. **Sort by county and city at diagnosis**
   Look at city and county to identify any miscodes or misspellings. Download the free Address Validation program provided by CCR at http://www.schs.state.nc.us/SCHS/CCR/ and then click on CCR Reporting Requirements and NC CCR Address Validation. We are required by the US Postal Service (whose data are used in the application) to request users of the application to sign a form promising not to redistribute these data. Please fax the signed agreement and you will be contacted with a password so that you can download and install the application. Specific questions about the application should be directed to Christian.Klaus@ncmail.net or 919-715-4475.

After you have investigated any cases that are questionable and corrected the database, you are ready to run the Primary Site Table. This should be generated on the entire year's cases (Analytic and Non-Analytic), utilizing the AJCC TNM Best Stage for cases diagnosed prior to 2008 and Collaborative Stage for cases diagnosed on or after 1-1-2008.

10. **Stage of Disease at Diagnosis.**
    Less than 10% of the analytic cases should be coded as "Unstaged." If any primary site has more than 10%, the cases need to be reviewed to see if a stage can be assigned. Document in the Staging Field the reason why a case cannot be staged.
    - "Blank" stage category - If any cases fall into this category, they need to be reviewed and corrected.

- "Not Applicable" Stage - Leukemias, multiple myeloma, unknown primary, and some sarcomas do not have AJCC TNM Staging so they are coded 88. Verify that only those legitimate sites are included in this column.

Running the file through GenEDITS Plus will further insure validity of the data and will facilitate error-free CCR/NCDB submissions.

Data accuracy and completeness are of paramount importance and all Cancer Program Coordinators should review the data prior to summarizing the year's cancer experience – either for submission to the CCR/NCDB or for the hospital annual report. This annual review allows for an overall evaluation of the entire year's data and will often identify omissions or errors that were missed during the abstraction and edit process. After you have completed these validation reports on the year's cases, you can be reasonably certain that your data is complete and accurate.

Do you have additional edits that you use to insure complete and accurate data? If so, please share them with the ANCCR group.

The March/April 2008 issue of the NC Medical Journal is titled "Data and Health Policy." There are a number of interesting health data related articles in this issue, including one related to the NC Central Cancer Registry titled "Cancer Surveillance and Its Use to Reduce Cancer Burden in North Carolina" written by Karen L. Knight, MS; Paul A. Buescher, PhD; Walter L. Shepard, MA.

Check it out at: http://www.ncmedicaljournal.com/mar-apr-08/knight.pdf.

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The July/August 2008 issue of the NC Medical Journal is titled "Creating a Community to Combat Cancer." If you haven't seen this issue, please check it out! The entire issue is devoted to cancer, and there's a great article that will hopefully bring more awareness to our profession titled "The Cancer Registry Profession: A Unique Role in Cancer Care and Control" written by Karen L. Knight, MS; Melissa Pearson, CTR; Wendy Tingle, CTR; Nora Landry, CTR; Tara Lewis, CTR; Eileen Morgan, MPA, CTR; Cathy Rimmer, MDiv, CTR.

Check it out at: http://www.ncmedicaljournal.com/mar-apr-08/knight.pdf

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2009 ANCCR Educational Meeting
August 26-28, 2009
Doubletree Biltmore Hotel
Asheville, NC

Please contact Tara Lewis with any questions.