

Advanced Abstracting: Breast Cancer

FOLLOW-UP, OUTCOMES AND QUALITY REVIEW

Part 5



Follow-up

- ◆ Plan ahead
- ◆ Collect contact information
- ◆ Anticipate data needs
- ◆ Determine amount of data to collect

2



Planning for follow-up while you are abstracting might take a little more abstracting time, but it will save much more time when that patient comes up for follow-up. Check for incomplete treatment. Write notes about anticipated care the patient might need in the future. Unfortunately, this is more practical for patients who are diagnosed with extensive disease. Anticipate data needs that will depend on follow-up information. Determine up front the amount of data you will collect at follow-up.

Plan Follow-up

- ◆ Set up follow-up when abstracting
- ◆ Identify likely contacts
- ◆ Anticipate patient's future healthcare needs
- ◆ Collect list of helpful web sites
- ◆ Make notes in abstract

3



There are several steps in planning ahead:

1. Looking up and entering zip codes to facilitate auto-letter generation for follow-up;
2. If the patient had a lumpectomy, make a note to check for radiation therapy;
3. Collect useful web site links and add them to your Favorites;
 - Social Security death index
 - Property tax collector's site
 - Physician locator for your state
4. Collect complete contact information;
5. Record the method you used to get the last contact information;
6. Enter the best method for getting good information at the next follow-up.

Collect Follow-up Contacts

- ◆ Complete patient address
- ◆ Spouse name and work number
- ◆ Identify health care surrogate
- ◆ Other family
- ◆ Other contacts

4



- Have a complete and current address and phone number for the patient.
- If the patient has more than one residence, collect contact information for all.
- Add the spouse's name and work number to your contact file.
- Identify the patient's health care surrogate (saves time if you know you can discuss the patient's cancer).
- Add family members to your contact file.
- Add other contacts that may keep track of the patient, like friends and neighbors.

Make sure you follow your facility's privacy policies. Don't leave protected health information on a patient's voicemail. Don't mention a patient's diagnosis to a friend or family member unless you are sure the patient identified that person as someone who can get that information. Just because a patient lists their next door neighbor as an emergency contact on their hospital admittance form doesn't mean that person has permission to receive or give out medical information on the patient. The neighbor may be listed because they provide transportation for the patient or take care of the patient's children.

Health Care Contacts

- ◆ Following physicians
- ◆ Other facilities that treated in past
- ◆ Home health care agencies if appropriate
- ◆ Hospice if appropriate

5



Collect contact information for the health care professionals that interact with your patient:

- Referring and following physicians;
- Treating physicians, especially physicians that are not on your facility's medical staff;
- Other facilities that treated the patient, including the cancer registrars;
- Home health care agencies if the patient was referred to one;
- Hospice if the patient was referred to one.

Anticipate Data Needs

- ◆ Survival and outcomes studies
- ◆ Recurrences
- ◆ Requirements for CoC approval
- ◆ Your facility's needs

6



Anticipate data needs for the future.

- What data will you need to calculate survivals?
- What type of outcomes studies can you expect to be asked for?
- What types of data will your facility need?
- Last but not least, what outcomes data are required by state and national standard setters (for example, the Commission on Cancer).

If you haven't planned ahead and set up your contacts, how are you going to collect the following required data?

- Date of first recurrence
- Type of first recurrence
- Current date of last contact
- Vital status
- Cancer status

You aren't the only one using your data. Data are collected by other agencies who depend on your outcomes data to make decisions about where to focus cancer care and cancer research.

Amount of Data to Collect

- ◆ Abstract now for data requests
- ◆ Determine data needs
 - Facility
 - Physicians
 - Research
- ◆ Determine amount of data to meet needs

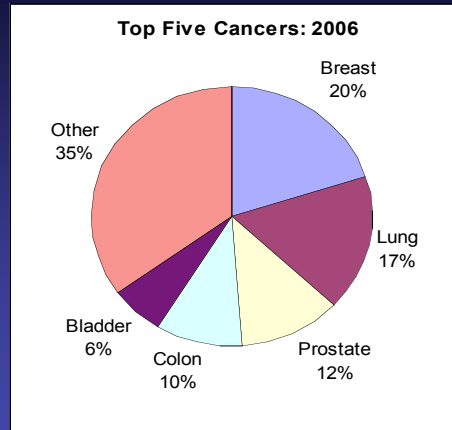
7



It's the same question discussed previously, but now apply it to follow-up data. Abstract now for the data requests you will get later. Be accurate with what you enter now, and determine future data needs for your facility, staff physicians, and research (at whatever level your facility participates). Determine, too, the amount and type of data needed to meet your needs.

Facility Data Needs

- ◆ Cancer site distributions
- ◆ Top cancer sites
- ◆ Trends over time
- ◆ Demographic distributions



8



Some common requests by administrators and staff in community hospitals include distributions of cancer sites seen at the facility, distributions of demographics (gender, age, race, ethnicity, zip code), the top cancer sites (note in the pie chart that only five sites account for approximately 2/3 of all cancer patients at that facility), and trends over time (any cancer site increasing or decreasing in numbers of cases more than the average).

Physician Data Needs

- ◆ Number of certain procedures
- ◆ Numbers of types of breast cancers
- ◆ Outcomes on certain therapies
- ◆ Outcomes on certain stages
- ◆ Other

9



Staff physicians want to know what kinds of procedures are being done at the facility. When they find out you collect patient procedures done at other facilities, they may want to know if there is a pattern of patients going elsewhere for a particular procedure. For example, although the facility has a perfectly good radiation therapy center, are patients having a lumpectomy in the facility and going elsewhere for adjuvant radiation therapy, such as the new mammosite procedure? Physicians may ask for the outcomes on certain stages or certain therapies. Outcomes can include readmissions, recurrences, disease-free intervals, and lifetime survivals, as well as other information.

Research Data Needs

- ◆ Know what data your facility needs
 - Teaching hospitals do research
 - Hospitals participate in clinical trials
- ◆ Studies required for CoC-approval
- ◆ Special studies not limited to your facility



10

What research data does your facility need? Teaching hospitals do research. Community hospitals may participate in clinical trials. Some smaller hospitals may just refer patients to other facilities for clinical trials but still want to track them. Any facility can do retrospective studies on cancer registry data. CoC-approved facilities are required to do studies. State registries may use your data for special studies.

The important point here is that *someone* should be using your data after all of the effort you have made to get the data into your registry.

Recurrences

- ◆ 2007 multiple primary rules: breast cancers more than five years apart are multiple primaries
- ◆ New occurrences within five years
- ◆ Assumes same site or metastatic site
- ◆ Assumes same histology
- ◆ Used for calculating disease-free survival

11



The 2007 multiple primary rules state that a cancer in the same breast with same histology diagnosed five years after an initial cancer is a different primary, even if the physician calls it a recurrence. The old rule was to assume a new primary after two months, unless the physician called it a recurrence. In order for a breast cancer occurring five years later to be called a recurrence, there must be documentation that a pathologist reviewed tissue from both tumors and said they were the same cancer.

Prior to the 5 years, a cancer may be called a recurrence by a physician. When collecting recurrence information, the date of the recurrence is important. The recurrence date establishes the length of the disease-free survival. If the recurrence wasn't diagnosed at your facility, you may have a problem establishing an accurate date when the recurrence was diagnosed. Your registry should have a policy on either estimating dates or using unknown values (i.e. 99/99/9999). You are also required to code the type of recurrence. Become familiar with the list of recurrence types. The first recurrence type you spot on the list that looks like a match may not be the most accurate match. Check the entire list when you have a recurrence before selecting a code—at least until you are familiar with the choices.

Status at Last Contact

◆ Cancer status

- Was the cancer present at last contact?
- Needed to calculate relative survivals

◆ Vital status

- Is the patient alive or not?
- Needed to calculate life-time survivals

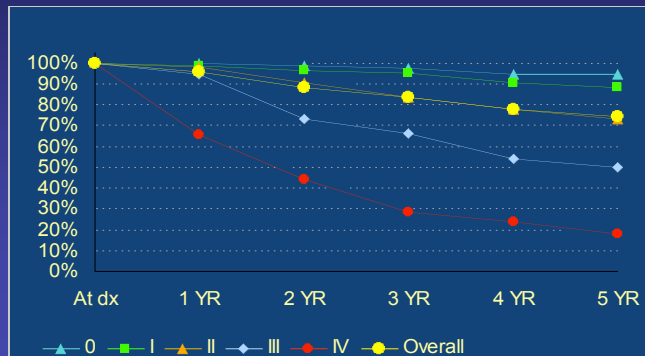
12



Along with recurrence information and the last contact date, vital status and cancer status are the most important data items you collect that will allow you to calculate outcomes. Disease status at last contact is needed to calculate relative survivals. Vital status is required for calculating life-time survivals.

Outcomes

- ◆ Use the data you've collected
- ◆ Outcomes studies required by CoC



13



Even if your facility is interested only in the minimum outcomes analyses to maintain approval status, your data goes to the larger state and national databases that will use it for analysis, to allocate funds for research, and to investigate disease clusters, among other uses.

Sometimes it pays to become proactive in presenting data and not wait until it is specifically requested.

QA Right Away

- ◆ Review as soon as you abstract
- ◆ Did you enter what you thought?
- ◆ Does it make sense?
- ◆ Run computer edit checks

14



Cancer registries are required to have a plan for quality assurance of cancer registry data. Usually the plan includes some type of review or reabstracting months after the abstract is completed. Actually, the best time to quality review your work is as soon as you finish the abstract. Can you code the case using the text that you've entered in the abstract? Does the abstract make sense? Did you enter typos or did you enter what you meant to enter? Quality reports should be run often to scan for discrepancies, tumor size versus stage of disease. For example, run computer program edit checks. Do quality review right away while the facts of the case are still fresh in your mind. The main benefit is that the case is accurate before you close it, and you don't have to revisit it later.

When you pull data for a study, look for outliers, values out of range for the norm. For example, breast tumor sizes over 10 cm. Maybe 10 mm was the actual size. If you find a mistake in one case, run a QA report on that same field in all cases to ensure the error isn't something done consistently. Run each year's data through NAACCR and NCDB edits long before reporting the data. That way any mistakes are caught, corrected early, and measures are implemented to keep the same mistakes from happening again.

Resources Used

- ◆ *United States Cancer Statistics: 2004*
(www.cdc.gov/uscs)
- ◆ NCCN Physician Guidelines: Breast, NCCN
(www.nccn.org)
- ◆ “How is Breast Cancer Treated,” American Cancer Society (www.cancer.org)
- ◆ *Facts & Figures 2007*, American Cancer Society
(www.cancer.org)
- ◆ *Breast Cancer*, Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
(www.hopkinshospital.org)

15



This presentation was compiled from a variety of sources. You may be interested in reviewing some of these for further information.

Sources

- ◆ *Cancer Stat Fact Sheets: Cancer of the Breast*, SEER web site (<http://seer.cancer.gov/statfacts>)
- ◆ *Female Breast Cancer*, SEER, (<http://seer.cancer.gov>)
- ◆ *AJCC Cancer Staging Manual*, 6th ed., AJCC
- ◆ *FORDS*, Commission on Cancer
- ◆ *ICD-O-3*, World Health Organization

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

17



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Cancer Prevention and Control Programs
and the
National Program of Cancer Registries**

Please visit

www.cdc.gov/cancer/npcr

