The Cancer Registry

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Objectives

- What is a Cancer Registry and types of Cancer Registries.
- The history of Cancer Registries.
- Reasons for maintaining a Cancer Registry and what information is maintained.
- How is registry data used and who uses it.
- How is registry data collected.
- What is a Cancer Registrar; their roles and responsibilities.
- See how the flow of information gets into the registry and beyond.
- How to become a Cancer Registrar and how to get certified.

What is a Cancer Registry?

An information system designed for the collection, management, and analysis of data on patients diagnosed with cancer.
Ultimate Goal

- To prevent and control cancer and improve patient care.
- Provide evidence-based information to physicians that is used to assess the efficacy of varying diagnostic and therapeutic methods.
- Cancer data collected on a local or regional basis allows for those working in a health care setting to manage the flow of patients and ensure that adequate resources are available – resulting in increased or better capacity of care.

Type of Cancer Registries

- Hospital registries: Maintain data on all patients diagnosed and/or treated at a particular facility. These registries usually report their cases to central or state cancer registries as required by law.
- Central registries: Population-based registries maintain data on all cancer patients within certain geographical areas.

Type of Cancer Registries – con’t

- State Cancer Registries: Monitors cancer within the state’s boundaries. All health care facilities are mandated by law to report all cancer cases.
- Special purpose registries: Maintain data on a particular type of cancer, such as brain tumors.
History of Cancer Registries

- 1923 – First hospital registry was created at Yale-New Haven Hospital in New Haven, CT.
- 1932 & 1946 – First central cancer registries were formed in Connecticut and California.
- 1956 – American College of Surgeons Commission on Cancer required all approved cancer programs to have cancer registries.

History of Cancer Registries – con’t

- 1973 – Surveillance, Epidemiology and End Results (SEER) Program of NCI established the first national cancer registry.
- 1974 – Nationwide cancer registration begins & NCRA is chartered.

History of Cancer Registries – con’t

- 1992 – Congress establishes a National Program of Cancer Registries – established registries in states where they did not previously exist.
- 1993 – State laws make cancer a reportable disease.
- 1996 – ACoS CoC requires data submission to National Cancer Data Base.
Reasons for Maintaining a Cancer Registry

- Local, state and national cancer agencies use registry data to define areas to make important public health decisions to maximize the effectiveness of limited public health funds.
- Cancer Registries are a valuable research tool for individuals interested in diagnosis and treatment of cancer, and for fundamental research on the epidemiology of cancer.

Reasons for Maintaining a Cancer Registry – con’t

- Cancer Registries maintain lifetime follow-up on cancer patients that serves as a reminder to physicians and patients to schedule regular clinical exams and provide accurate survival information.

What info is maintained in a Cancer Registry?

- Demographic info: Age, gender, race, birthplace and residence.
- Medical history: Physical findings, screening info, occupation/industry and any history of previous cancer.
- Diagnostic Workup: Types, dates and results of procedures used to diagnose cancer.
What info is maintained in a Cancer Registry? – con’t

- Cancer Information: Primary site, cell type and extent of disease.
- Cancer treatment: Surgery, radiation therapy, chemotherapy, hormone and immunotherapy.
- Follow-up: Annual information concerning treatment, recurrence, and patient status is updated to maintain accurate surveillance information.

How is Registry Data Used?

- Evaluate patient outcomes, quality of life, and implement procedures for improvement.
- Provide follow-up information for cancer surveillance.
- Calculate survival rates.
- Provide information for cancer program activities.
- Analyze referral patterns.
- Allocate resources at the hospital, the community, region or state level.

How is Registry Data Used? – con’t

- Develop educational programs for Physicians, allied health care workers, patients and the community.
- Report cancer incidence as required under state law.
- Evaluate the efficiency of cancer treatment modalities.
- Improve patient care.
Who uses the data

- Detailed cancer information is collected at health care facilities, such as doctors' offices, hospitals, and clinics.
- Data are compiled and reported to central, state or regional registries.
- Data are sent by central registries to one or both national registries
  - Surveillance, Epidemiology, and End Results Program (SEER) at the National Cancer Institute and the National Program of Cancer Registries (NPCR) at the Centers for Disease Control and Prevention.

Who uses the data – con’t

- The National Cancer Institute’s SEER Program is a national population-based cancer registry that monitors a representative sampling of certain geographic areas or about 26% of the U.S. population.
  - The data are used to determine representative national cancer incidence, mortality, and survival rates.
  - The SEER Program is also a data standard setting organization for cancer registries.

Who uses the data – con’t

- SEER data currently comes from the states of California, Connecticut, Iowa, Kentucky, Louisiana, New Jersey, New Mexico, Utah, and Hawaii as well as metropolitan areas of Atlanta, Detroit, Los Angeles, San Francisco-Oakland, San Jose-Monterey, and Seattle-Puget Sound (Cancer Surveillance System of Fred Hutchinson Cancer Research Center)
  - Covers 9 states, 6 Metro Areas and 26% of the population.
Who uses the data – con’t

- The CDC’s National Program of Cancer Registries (NPCR) provides funds and technical assistance to improve cancer registration throughout the United States.
  - The database is used to monitor the burden of cancer for the nation – covers 96% of population.
  - Data are provided for research, evaluation of cancer control activities and to plan for future healthcare needs.
  - NPCR is a data standard setting organization for cancer registries.

Who uses the data – con’t

- Hospitals accredited by the American College of Surgeons (ACoS) Commission on Cancer are required to submit their data to the National Cancer Data Base (NCDB)
  - The NCDB is a multi-hospital database that monitors cancer care in ACoS Approved Cancer Programs.
  - The information collected is available for comparisons of care studies and other quality improvement initiatives.

How is the data collected?

- There are many techniques and languages used in Cancer Registries to collect data.
  - North American Association of Central Cancer Registries (NAACCR) – Data Standards and Data Dictionary for Cancer Registries
  - International Classification of Diseases for Oncology – ICD-0, 3rd Edition
  - Commission on Cancer - Facility Oncology Registry Data Standards (FORDS), and
  - Cancer Program Standards
How is the data collected? – con’t

- National Program of Cancer Registries (NPCR)/CDC – Software & Tools
- American Joint Committee on Cancer - (AJCC) TNM Staging Manual, 7th Ed., and 
  Collaborative Staging Manual
- SEER/NCI - Multiple Primary & Histology Coding Rules (MP/H),
  - SEER Program Coding and Staging manual
  - Hematopoietic Database

What is a Cancer Registrar?

- Data management expert who reports cancer statistics for various healthcare agencies.
- Works closely with physicians, administrators, researchers, and health care planners to provide support for cancer program development, ensure compliance of reporting standards, and serves as a valuable resource for cancer information.
- Is involved in managing and analyzing clinical cancer information for the purpose of education, research and measuring outcomes.

Primary Responsibility of the Cancer Registrar

- Ensure that timely, accurate and complete data is collected and maintained on all types of cancer diagnosed and/or treated within an institution or other defined population.
- Abstract an account of the cancer patient’s history, diagnosis, treatment, and current status. Information is entered manually and through database linkage and computer interfaces.
Primary Responsibility of the Registrar – con’t

- Bridge the information gap by capturing a complete summary of the patient’s disease from diagnosis through their lifetime.
- Participate in cancer program, institution, and community benefit activities as part of the active leadership structure.

Primary Responsibility of the Registrar – con’t

- Provide benchmarking services, monitor quality of cancer, clinical practice guidelines, assess patterns of care and referrals, and monitor adverse outcomes including mortality and co-morbidity.
- Provide consultative services on many issues including registry management and program standards.

Roles in the Cancer Registry

- Abstractor – Must be a CTR
- Case finding – identifying cases to be abstracted.
- Tumor Board Coordinator – Coordinates the cancer conferences where patient treatment options are discussed by a multi-disciplinary group of physicians.
- Follow-Up Coordinator – Obtain follow-up information on patients needing annual surveillance.
### Roles in the Cancer Registry – con’t

- Cancer Committee – Registrars work with physicians and administration to improve the quality of the cancer program.
- Data Quality Control – Reviews abstracts to ensure that the data has been collected correctly and is complete. – Good data in means good data out.
- Data Reporting – Submits data to reporting agencies as well as queries the database and reports pertinent information to the Cancer Committee or others needing the information.

### Roles in the Cancer Registry – con’t

- Maintains Registry Policies & Procedures.
- Training – Continual training is necessary as data standards change frequently and registrars must learn new rules and data fields to be collected.
- Data analysis – run special reports, analyze survival data and referral patterns.

### Roles for Registrars outside of the Cancer Registry

- Hospital Administration
- Outsourcing or Contract services
- Government Agencies
- Software Vendors
- Pharmaceutical Companies
The Flow of Cancer Information

- How does cancer information move from diagnosis at the local level to become part of national cancer data?
- The following is a scenario that may occur in our registry of how a patient is diagnosed and brought to treatment and then abstracted into the registry.

Diagnosis

- After feeling a lump in her breast during a breast self-exam, Susie Homemaker goes to her primary care physician who refers her for a mammogram—done at a free standing breast diagnostic center. The mammogram is read as suspicious and she is referred for a biopsy. This happens a few days later. Susie then learns from her doctor that the biopsy was positive for breast cancer. Her doctor refers her to a surgeon.
- Susie’s surgeon orders further tests (i.e. ultrasound, MRI, blood tests) that are done at a free standing breast diagnostic center.

Treatment

- Susie’s surgeon then presents her case at Breast Conference for discussion of treatment options. Susie’s surgeon than proposes a treatment plan which will include a lumpectomy, radiation therapy and systemic therapy.
- Susie’s surgery is completed in the hospital, and she is determined to have Stage I breast cancer.
- Her record is coded and an ICD-9 code for breast cancer is assigned to her record.
Determining Reportability

- A copy of Susie’s path report is also sent to the Cancer Registry to be reviewed. Her surgical pathology report and the ICD-9 code that was assigned to her surgical record prompts the registry to review her medical record along with reports from all her pre-surgical workup to determine if Susie has a “reportable” diagnosis.
- The Cancer Registrar will determine if Susie is already in the hospital’s registry. She is not, a new record is added to the registry database. The case is “abstracted” into the registry.

Query for Missing Treatment

- The Registrar examines Susie’s medical record to determine where she is being treated and what treatment she is receiving.
- Susie was treated with a six-week course of radiation therapy at a local free-standing radiation center following her surgery. This information will be obtained either from the managing physician or directly from the free standing radiation center that treated Susie.
- Susie also met with a Medical Oncologist to discuss systemic therapy. The Registrar will contact the Medical Oncologist to obtain this information.
- Susie was started on hormonal therapy – Tamoxifen.
- Once the missing treatment information is obtained, it will be entered into Susie’s record to complete her abstraction.

Quality Control Review and Data Submission

- After Susie’s breast cancer has been abstracted into the Cancer Registry, her abstract will be reviewed for quality assurance. The information on the abstract will be compared to the hospital medical record and any additional information gathered from outside sources to determine if the data was collected and coded correctly following correct standards.
- Once finalized, the data is sent to the SEER registry (CSS) and to the state registry (WSCR).
- Also, because our facility is an approved program, the data will also be sent to the National Cancer Data Base.
Follow-Up

- After Susie’s initial treatment is complete, she will return to her oncologist for follow-up. Re-staging scans and blood tests are done and she is determined to be disease free, but she is to continue her follow-up with her oncologist every six months.
- Follow-up will be maintained annually by the Cancer Registry.

What a Cancer Registrar needs to know

- The Cancer Registrar must gather information from multiple sources, including each of the places where a patient has received care such as the hospital, free-standing radiation therapy clinics, or an oncologist’s office.
- The Cancer Registrar must understand what data are useful and ensure that they are accurately and completely entered into a database.

What a Cancer Registrar needs to know – con’t

- The Cancer Registrar must have a thorough understanding of computer systems and know how data will be shared with central registries and ultimately used.
- Finally, the Cancer Registrar must have a complete knowledge of the illnesses faced by patients living with cancer and the vast number of treatment options used to treat different forms of cancer.
Cancer Registrars are Key Players

- Cancer Registrars must interact with physicians, administrators, researchers and health care planners.
- Cancer Registrars not only gather information, but also share information about specific patient's histories and treatment results, and note trends in cancer diagnoses in health care facilities and communities.

Cancer Registry is a dynamic profession

- Cancer Registrars tend to love their work.
- Cancer Registrars are dedicated, enthusiastic, and self motivated professionals – who work with minimal supervision.
- Cancer Registrars are detail oriented, not just in data collection but also in the data analysis.
- Cancer Registrars are multi-tasks able to perform multiple tasks at once.
- Cancer Registrars work closely with physicians and administrators.

Cancer Registry is a dynamic profession – con’t

- Cancer Registrars perform a wide variety of interesting tasks, including data analysis.
- Cancer Registrars have medical and scientific knowledge but without hands on patient care.
- Cancer Registrars get their greatest satisfaction from knowing that their work contributes to the knowledge of cancer, the improvement in patient care and valuable research on new medical technologies.
Today’s Growing Problem

- By 2020, there will be a 48% increase in cancer incidence.
- Will need 800 new Registrars to meet this demand.
- The Median Age of Cancer Registrars is 48.
- Change by CoC to require CTRs in the new standards


Today’s growing problem

- There is a shortage of cancer registrars
  - Without an adequate number of well-trained cancer registrars, accurate, dependable and timely cancer research and statistics reporting will be compromised.
- HIM professionals historically have been one of the major areas of career progression into the cancer registry field. Their training makes them uniquely qualified to transition into the field of cancer registration with minimal additional training.

How Do You Become a Cancer Registrar?

- Traditionally, Cancer Registrars came from other allied health fields such as HIM or nursing and were trained on the job.

Due to the advent of national cancer reporting and an emphasis on quality assurance, formal education programs have greatly expanded.
How Do You Become a Cancer Registrar? – con’t

• Today, attend an accredited formal education program at colleges around the country that teach cancer data management.
  – Curricula includes: Cancer and its management, medical terminology, anatomy and physiology, biostatistics and epidemiology, cancer data abstracting, database record management, cancer program management and cancer registry procedures.
  – Combined with on-the-job training.

How to Become Certified

• The National Cancer Registrars Association’s (NCRA) Council on Certification administers an examination.
• After successfully passing the certification examination, become a Certified Tumor Registrar (CTR).

Benefits of Certification

• Certification enhances data quality,
• Fosters professional pride, and is
• Nationally recognized in recruitment and retention of registry personnel.
• Promotes excellence in the Cancer Registry field by establishing a standard of knowledge and experience required for professional registry practice.
I believe that the quality of the data collected by a CTR is equally as important as patient care. If we want to understand our care, to analyze it and improve outcomes, then we must have good data. And the quality of the register professional is vitally important to having this quality data.

—— Ava Corn, CTR, Manager of Certification and Compliance Services, Montana College of Emergency Health Professions

THANK YOU!!

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