

Cancer as a Disease

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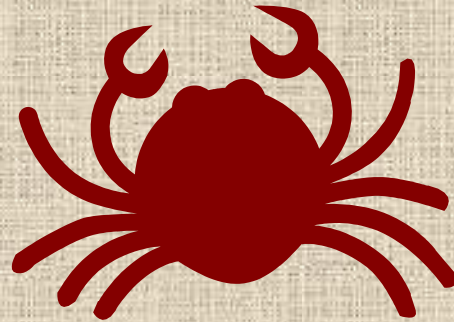
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Historic perspective

- **First records date as early as 2500 B.C.**
 - In Egypt recorded on papyrus
 - Outlines pharmacological, mechanical and magical treatments
- **Greece and Rome dominated medical thought for 1,500**

The name “cancer”

- Hippocrates credited with naming “cancer”
- Tumor looked like a crab
 - Body of the tumor – body of crab
 - Tumor extension – legs of crab



General definition of cancer

- **Characteristics of cancer**
 - **Abnormality**
 - **Uncontrollability**
 - **Invasiveness**
 - **Group of diseases**

Characteristics of cancer

- **Abnormality**
 - Cells are structural units of all living things
 - Cells make possible all functions of life
 - Cancer cells stop functioning or behaving as they should
 - Cancer cells serve no useful purpose in the body

Characteristics of cancer

- **Uncontrollability**
 - Normal cells regulate the ability to reproduce by dividing
 - Cancer cells divide in a haphazard manner
 - Cancer cells pile up into a non-structured tumor or mass

Characteristics of cancer

- **Invasiveness**
 - **Some tumors do not stay harmlessly in one place**
 - **They destroy the part of the body they originated**
 - **They start a new growth and cause more destruction**

Characteristics of cancer

- **A group of diseases**
 - **More than 100 different disease**
 - **All characterized by uncontrolled growth and spread of abnormal cells**
 - **Can arise in many sites and behave differently depending on its origin**

Site of cancer

- **Can arise in any organ or tissue**
- **Primary site = part of the body in which the cancer first develops**
- **Secondary site = part of the body where metastasized cancer cell grow and form**

Cancer classified by stage

- **Staging describes how far a cancer has progressed based**
 - **Size of primary tumor**
 - **Where it has spread**

What is the preferred method to confirm the diagnosis of cancer?

- **A biopsy is the preferred method**

What kind of information can a biopsy provide?

- **Histologic type**
- **Classification**
- **Grade**
- **Potential aggressiveness**

Cancer Registration

What is a cancer registry?

- **A particular type of disease registry with**
- **3 main purposes**
 - **1. establish and maintain cancer incidence reporting system**
 - **2. to be an informational resource for the investigation of cancer and its causes**
 - **3. to provide information to assist public health officials and agencies in the planning and evaluation of cancer prevention and cancer control programs**

What is cancer registration?

- **Process of continual, systematic collection of data on the occurrence and characteristics of reportable malignancies**
- **Purpose of helping to assess and control the impact of cancer on the community**

What is a cancer registrar?

- **Person trained to collect accurate, complete, and timely data on cancer patients**

Types of cancer registries

- **2 major types**
 - **1. Hospital-based registries**
 - **2. Population-based registries**

What kind of registry do we have?

- You are actually hospital-based registrars who perform all the duties of other hospital-based registrars and also serve as a population-based registry**
- That is, you may work in a hospital setting but you are responsible for the collection of ALL cancer cases for your population (jurisdiction) whether they are admitted to your hospital or not**

You are a super registrar!

- Able to work within the hospital as well as within the community
- Able to work with public health officials within the government as well as the staff of the hospital



Goals of hospital-based registries

- **Improvement of patient care**
- **Professional education**
- **Administrative Information**
- **Clinical research**

Goals of population-based registries

- **Cancer prevention**
- **Early detection**
- **Determination of cancer rates and trends**
- **Patterns of care and outcomes**
- **Research**
- **Evaluation of control efforts**

**And you can do it all
because...**

You are Super Registrar!



Cancer data

- **Four categories**
 - 1. patient demographics
 - 2. tumor (cancer) identification
 - 3. treatment
 - 4. outcome

Patient Demographics

- **Personal information about patient**
 - **Name, age, gender, race, ethnicity, birthplace, residence, etc.**
 - **This information helps to check for duplicate registrations**
 - **Data would be inaccurate and unsuitable for analysis without demographic information**

Cancer identification

- **Diagnostic information about the patient**
 - **Primary site, cell type, extent of disease**
 - **Includes dates and results of procedures used to diagnose cancer**
 - **Both in text and in codes**

Treatment

- **Information about surgery, radiation therapy, chemotherapy, hormone therapy, immunotherapy and other therapy**
- **Both in text and in codes**

Outcome

- **Cancer registries continue to gather data after the cancer patient has received treatment.**
 - **Information concerning the outcome of the treatment**
 - **Patient vital status**
 - **Patient tumor status**
- **Lifetime follow-up on patients**

Process of cancer data collection

- **Begins by identifying people with cancer**
 - **In hospitals**
 - **Outpatient clinics**
 - **Doctor's office**
 - **Radiology department**
 - **Office laboratories**
 - **Surgery center**
 - **And anywhere else patient is diagnosed or treated**

Process of cancer data collection

- By law all cancer cases, no matter where the patient was diagnosed, need to be reported to the central registry**
- You may be both the hospital registrar and central registry registrar for your jurisdiction**

Process of cancer data collection

- **NOT A PASSIVE PROCESS**
 - Registrar does not wait for cancer information to be handed over
 - Registrars are actively involved in casefinding by visiting the sources of the cancer diagnosis and treatment information
 - Registrars must adopt their own innovative data collection system for their jurisdiction to make sure that all cancers are counted

Process of cancer data collection

- **IT'S HARD WORK**
- **But it is work of great value**
- **Your hard work is worthwhile**

Confidentiality

- **Cancer data is highly confidential**
- **It is one of your most important responsibilities**
- **Adhere to the law of your jurisdiction regarding confidentiality**
- **Registrars must also adhere to policies to protect the privacy of the physicians and health care facilities**

Data Standards

- Rules set by the governing authority
- NAACCR is the governing authority for the reporting of cancer cases for all Central Cancer Registries
- The National Program of Cancer Registries (NPCR) is administered by the Centers for Disease Control and Prevention (CDC) is the reporting authority for your jurisdiction and it adheres to the NAACCR standards for Central Cancer Registries

Stands for data & data management

- **Cover the following topics:**
 - **Data sets**
 - **Code categories**
 - **Rules for code assignment**
 - **Data edits**
 - **Case consolidation**
 - **Cases to be covered by new or changed standards**
 - **Administrative items**
 - **Data Management Procedures**

Data sets

- **Lists of variables collected to meet the minimal requirements of the groups goals**
- **Often contain additional lists of elements that are recommended for most effective operation**
- **Required sets are not the same for all standard seters**

Code categories

- **Standard codes are necessary for reporting or exchanging data**
- **Standard categories must be retained in registry structure**
- **Greatest need is for consistent data**
 - **Data elements having the same intent should mean the same thing in every registry that collects them**

Rule for code assignment

- **Both technical and non-technical elements must follow rules for code category assignment**
 - **Examples:**
 - **How exactly does an abstractor select among the multiple reference to morphology in a record.**
 - **When does the first course of therapy begin and end?**

Data edits

- **Data edits test the logical effects of coding rules or natural relationships**
- **Data must be edited using the data sets developed for your data by your standard setter**
- **NAACCR has developed Standard Edits for Cancer Registries and their edits have been adopted by many standard setters**

Case consolidation

- Major function of central cancer registries
- Data from multiple reporting sources and facilities or institution are consolidated into one comprehensive case
- When data from multiple sources pertaining to the same person with the same cancer are combined there are inevitable discrepancies
- Consolidation rules determine which data inconsistencies can be resolved automatically and when to assign precedence of one category over another

Cases to be covered by new or changed standards

- **Over time introduction of new or revised codes is sometime necessary**
- **A date of implementation is specified for the new codes**
- **Sometimes the date specified is retrospective and previous cases need to be re-coded**

Administrative Items

- **Standard administrative codes identify code version or flag exception to standard edits**
- **Standard administrative items permit communication about the nature of the data in a form that can be interpreted by a computer program**
- **Sometimes these administrative items are not obvious to the registrar (hidden fields)**
- **Sometimes administrative items need to be added by the registrar**

Data management procedures

- **Scope of operations defined by NPCR**
 - **Staff training and qualifications**
 - **Case inclusion**
 - **Case ascertainment**
 - **Procedure for adding new cases to the permanent data set**
 - **Rules for updating or changing data on file**
 - **Follow-up**
 - **Data exchange**
 - **Data analysis and publication**