Maryland Department of Health and Mental Hygiene

Center for Cancer Surveillance and Control

Questions and Answers about

Cancer Clusters

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Maryland Cancer Registry
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Baltimore, MD 21201
410-767-4055
http://www.fha.state.md.us/cancer/registry

Apparent cancer clusters attract a great deal of media attention. The purpose of this booklet is:

- to provide a brief overview about "cancer clusters"; and
- to give information about the ways in which cancer cluster reports are investigated in Maryland.

What is a cancer cluster?

A "cancer cluster" is a greater than expected number of cases of similar cancers occurring in a defined period of time among people who live or work near each other.

Cancer Facts

Concerns about cancer clusters usually begin when a relative, friend, neighbor, or co-worker is diagnosed with cancer. This close contact with cancer often brings an awareness of other people who have cancer and a strong desire to identify a cause. Heightened awareness and a search for causes may lead to more questions. The following facts can help to answer some of those questions about cancer and cancer clusters:

Cancer is not just one disease.

The term "cancer" refers to a group of over 100 diseases that all start because abnormal cells grow out of control.

Cancer is a disease with many risk factors, only some of which are understood. Different types of cancer have been associated with various causes or risk factors, including genetics, lifestyle, and environment. For example, smoking is a known cause of lung cancer. Radiation and benzene are risk factors for certain types of leukemia, but not for colon cancer. Because of cancer's complex causes, we cannot immediately assume that cancers occurring in one place or at one time share a common cause.

Cancer is more common than most people realize.

Cancer is the second leading cause of death in the United States and in Maryland. Cancer was the cause of death for 24 percent of Marylanders in 2006.[1] According to the American Cancer Society, men have a little less than a one in two lifetime risk of developing some type of cancer (not counting skin cancer); for women the risk is a little more than 1 in 3.[2] This means that cancer strikes about three out of four families. Just a few types of cancer are very common—cancers of the breast, prostate, lung and bronchus, and colon and rectum account for approximately 58 percent of all newly diagnosed cancers in Maryland.[3]

Given these statistics, it is not unusual to learn that several people in a neighborhood or workplace may have cancer.

The risk of cancer increases with age.

Age is the most important risk factor for developing cancer. About three out of four people diagnosed with cancer in the United States are age 55 years or older.[2] Therefore, a community of older adults is expected to have more cancer cases than a community with younger people or a range of age groups.

Most cancers are related to lifestyle factors.

Medical researchers believe that the risk of cancers is related to how we live. Lifestyle factors such as smoking or other tobacco use, diet, obesity, and lack of exercise are believed to account for approximately two-thirds of all cancer deaths in the US.[3] Lifestyle factors often cluster in communities, as people tend to adopt the same habits and diet as their family, friends, and neighbors.

Toxic substances in the environment account for a relatively small percentage of cancer deaths in the U.S.

Many people believe that cancer is generally caused by exposure to toxic substances in the environment. However, researchers indicate that environmental exposures, *other than tobacco smoke*, may account for less than 10 percent of all cancers.

Cancers diagnosed today are usually related to events that happened many years ago.

Cancer is caused by both **internal factors** (such as gene mutations [both inherited and acquired later in life], hormones, age, and immune conditions) and **external factors** (such as exposures to tobacco, sun and other ultraviolet radiation, chemicals, X-rays, and infectious organisms). These factors may act together or alone to initiate or promote the growth of a cancer. Ten or more years often pass between the first cell mutations or a harmful exposure and the detectable cancer. This long period makes it very difficult to pinpoint the specific causes of many cancers.

Cancer clusters can occur by chance.

For some cancer types and some geographic areas, a small number of cases may be enough to change an area's cancer rate from below average to above average. While the increase may be real, the additional cases may simply be the result of variations that occur randomly or by chance, and not be due to a single cause. Many communities have below average cancer rates and many others have above average cancer rates. Small communities tend to be more different from average while larger communities tend to be closer to average just because in a small community, just a few cases can make a big difference to the rate.

These cancer facts must be kept in mind when the health department receives a report from a person about a suspected cancer cluster in his or her neighborhood or workplace.

How are clusters investigated in Maryland?

Reports of suspected cancer clusters are taken seriously. Several local and state agencies can be involved in the process. Local health departments are included in handling reports of clusters because they have knowledge of local health and environment issues and insight regarding local residents' concerns. They are also typically the first point of contact for concerns about possible clusters.

By law, the Maryland Cancer Registry of the Department of Health and Mental Hygiene collects cancer information each year from hospitals, laboratories, cancer treatment centers, and doctors on all new cancer cases diagnosed in Maryland (excluding basal and squamous cell skin cancer). Because the Maryland Cancer Registry has information about the number, type, and location of cancers in Maryland, its staff participates in all three aspects of the investigation (listed below). Other units of the Department of Health and Mental Hygiene and other state agencies, such as the Maryland Department of the Environment and the Maryland Occupational Safety and Health program, may also be involved.

Step 1: Initial Information

The first step in a cancer cluster investigation involves evaluating information about each cancer case thought to be part of a cluster.

Ideally, information is needed on each person with cancer, such as the age, sex, type of cancer, year of diagnosis, and the geographic area of residence. If an environmental exposure is suspected, then it is important to know the work site or location at the time of exposure. This initial information is used to determine if the cases fit the profile of a cancer cluster. The concerns raised by the caller must be carefully assessed and discussed. In many cases, callers are reassured during the initial call or after looking at some statistics for comparison.

Investigators may need to check that all of the "cancer" cases are truly cancer. Some diseases may be mistaken for cancer and yet be reported as part of a "cancer cluster."

In addition, investigators ask about the **primary** location in the body of each reported cancer. Cancers that begin in different body locations generally have different causes and characteristics. Also, the primary (or initial) location of the cancer may be different from the final location due to a process called "metastasis," where cancer cells move about the body, settle, and grow in other tissues. In particular, cancer cells found in the brain, liver, or bone may actually come from a cancer that started elsewhere in the body (like breast, colon, or prostate sites).

The geographic place of residence at the time of diagnosis or exposure also must be known. If a cancer was diagnosed when the person lived or worked in another location, then the person with cancer cannot be considered part of a suspected cluster in the current area or workplace. A common mistake would be counting people who move into an area as having their exposure in the new area. This could artificially raise the cancer rates and make it look like a cancer cluster.

Step 2: Preliminary Investigation

If the possibility of a cancer cluster cannot be ruled out after studying the initial information, investigators conduct a preliminary statistical analysis. Numbers of cancer cases and cancer rates from the Maryland Cancer Registry are used to evaluate whether the rate of cancer is higher than expected and how likely it is that an increase in cancer rates could have occurred by chance. Maryland Cancer Registry data are available only to certain health officials in Maryland because data are confidential and protected by law.

In this step, investigators make a rough comparison between the actual or "observed" cancer cases, and the number of cancer cases we would expect based on known information about the cancer rate in the county or in Maryland as a whole. Certain statistical tests are done. If the observed number of cancer cases is less than the number of cases that would be expected, then there is no cluster. The investigation is completed and a report may be prepared on the findings.

If there is an increase over the expected rate, the suspected cluster is tested to see if it is "statistically significant." This is a way of measuring how likely the increase is due to chance. Depending on how statistically significant the suspected cluster is, the investigation may be completed and a report generated or the situation may continue to be monitored into the future. If this is confirmed, and the suspected cluster was unlikely to be due to chance, a more detailed investigation may be necessary.

Step 3: Further Investigation

If cancer data from the Maryland Cancer Registry show that the number of reported cases in an area is statistically significantly increased, then steps may be needed to better define the possible cluster and known risk factors. For example, if lung cancer rates are higher than expected, smoking rates are often higher too.

The goal of this phase is to confirm the existence of a cluster and provide hypotheses about the possible cause. The steps necessary to determine definitively *why* the cancer rate is elevated (that is, what risk factor(s) might be causing the cancer increase) take a bigger investigation that may take months or years to complete. Sometimes a cause cannot always be found.

In cases where a specific modifiable risk factor is identified, measures for protecting the public and actions to remove or reduce modifiable risks should be implemented. This could mean addressing lifestyle or environmental factors or access to medical care. Some risk factors are not modifiable such as genes, gender, or age.

The combined experience of many states and agencies involved with cancer cluster investigations suggests that statistically significant cancer clusters are extremely rare. Only about two of every 1,000 reports of suspected cancer clusters reach the step where a further investigation is required to identify common risk factors. However, every call regarding a cancer cluster report is an opportunity to learn more about cancer and to find the best ways to reduce risk.

[1]Source: DHMH Maryland Vital Statistics Annual Report 2006
[2]Source: American Cancer Society Facts and Figures, 2004
[3]Source: Maryland Cancer Registry, DHMH, 2001

For information about cancer and to contact State agencies in Maryland:

Maryland Cancer Registry, Center for Cancer Surveillance and Control
Maryland Department of Health and Mental Hygiene
410-767-4055
http://fha.maryland.gov/cancer/mcr_home.cfm

Maryland Department of Health and Mental Hygiene
Center for Cancer Surveillance and Control
410-767-5281
http://fha.maryland.gov/cancer/

Maryland Department of Health and Mental Hygiene
Environmental Health Coordination Program
410-767-6234/Toll-Free 1-866-703-3266
http://eh.dhmh.md.gov/

Maryland Department of the Environment
Science Services Administration
410-537-3000
http://www.msa.md.gov/msa/mdmanual/14doe/html/doe.html

Maryland Department of Health and Mental Hygiene
Maryland State Council on Cancer Control
410-767-1617
http://fha.maryland.gov/cancer/sccc_home.cfm

To report occupational-related health hazards, injuries, or illness:

Maryland Department of Labor, Licensing, and Regulation
Maryland Occupational Safety and Health
410-767-2241
http://www.dllr.state.md.us/labor/mosh/

For general information on cancer, cancer clusters, cancer prevention, and cancer treatment:

National Cancer Institute (NCI)
1-800-4-CANCER
http://www.cancer.gov/aboutnci/cis/page1
for cancer cluster information: *http://www.cancer.gov/cancertopics/factsheet/Risk/clusters*
http://www.cancer.gov/newscenter/Cancer-and-the-Environment

Cancer Information Service
1-800-4-CANCER
http://www.cancer.gov/aboutnci/cis.

The American Cancer Society
1-800-ACS-2345
http://www.cancer.org/

Centers for Disease Control and Prevention
Cancer Prevention and Control
1-800-CDC-INFO (232-4636)
http://www.cdc.gov/cancer/
http://www.cdc.gov/nceh/clusters/ for cancer cluster information

National Institute for Occupational Safety and Health (NIOSH)
1-800-232-4636
http://www.cdc.gov/niosh/

U.S. Environmental Protection Agency
http://www.epa.gov/

The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
410-955-5222
http://www.hopkinsmedicine.org/kimmel_cancer_center/

The University of Maryland Greenebaum Cancer Center
1-800-888-8823
410-328-7904
http://www.umgcc.org/

National Coalition for Cancer Survivorship
1-888-650-9127
http://www.canceradvocacy.org

Dana-Farber/Harvard Center for Cancer Prevention
http://www.dfhcc.harvard.edu/