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People are often concerned about what seems like an elevated number of cancer cases in their neighborhood or workplace and they may wonder whether a common environmental exposure is to blame. This technical brief explores the phenomenon of cancer clusters by:

- explaining how we identify cancer clusters;
- describing several well-known cancer cluster investigations;
- discussing reasons why cancer clusters are so difficult to link with an environmental cause; and
- recommending appropriate public health responses to citizens concerned about cancer clusters.

Defining a cancer cluster

The term "cancer cluster" is most often used to describe a greater than expected number of cancers occurring within a group of people, in a geographic area, over a period of time (CDC 2003). Epidemiologists know that cancer rates vary from year to year and use statistical tests to determine whether a particular cancer rate is

different enough from the average to qualify as "unexpected." They also identify whether a cluster involves only one type of cancer (particularly a rare cancer type), or a cancer type not usually seen in a particular population, as these factors indicate a greater likelihood that the cancer cases may have a common cause. Even when statistical tests indicate that cancer cases are higher than expected, the clustering can still be a random occurrence. Clusters of cancer cases can happen naturally, just like when five consecutive "heads" are part of a 50-50 distribution of 100 coin flips.



The public looks at cancer clusters in a very different way. People are alarmed by a diagnosis of cancer and naturally question the cause of their cancer. A cancer diagnosis often prompts people to focus on the occurrence of cancer among their friends, neighbors and co-workers and seek common causes or patterns in cancer cases. The general public usually lumps all cancers together, even when the tumors have entirely different risk factors. "Cancer" is actually an umbrella term that includes over 100 different diseases which develop through the uncontrolled proliferation of abnormal cells that have the potential to spread beyond the organ of origin. The public also forgets how common cancer is; affecting 1 out of every 2 or 3 of us in our lifetimes. Another factor that helps create the appearance of a cluster is the definition of the geographic boundaries of concern. Because some cancer cases will be randomly clustered, looking for a cluster when one already knows the location of the cancer cases is akin to drawing a bull's eye around a cluster of darts thrown at random. This is known as the "Texas Sharpshooter Fallacy." Finally, the general public is not good at identifying truly random patterns. Research shows that our intuitions of randomness differ clearly from statistically defined randomness (Siegrist et al. 2001). This is particularly true when there is a narrative (such as environmental pollution) to explain the cluster. People are very reluctant to believe the cancer cluster is only a coincidence.

Are cancer cluster inquiries common?

State and local health departments are frequently the resource citizens turn to when they are concerned about cancer and perceived patterns in cancer cases. The perception that cancer is occurring in clusters is a common one. According to a national survey conducted in 1998, state health departments across the U.S. received a total of about 1,100 requests to investigate cancer clusters (Trumbo 2000). This number is not dramatically different from the number reported in an earlier national survey done in 1989 (Greenberg & Wartenberg 1991). In Connecticut, the Department of Public Health receives an average of 20 cancer cluster calls per year, which is in line with the national figures. Although the number of cancer cluster complaints does not seem to be on the rise, state health departments report that the intensity of community concern about cancer clusters has increased (Trumbo 2000). Despite the high level of community concern about cancer clusters and the attention that health departments give to the follow-up of cancer cluster inquiries, the reality is that there have been only a few reported cancer clusters that have proved to be "real" clusters, with a statistically significant, persuasive environmental cause (McGlinn 2006, Goodman et al. 2012).

Over a period of 20 years beginning in the early 1960s, the Centers for Disease Control (CDC) actively sought cancer clusters to study potential clues to identifying human cancer-causing agents. In the 108 CDC cancer cluster investigations that resulted, no meaningful environmental causes explained any of the clusters (Caldwell 1990). The national surveys of state health departments similarly indicate that of the many cancer cluster complaints received each year, very few are determined to require significant follow-up investigation (Greenberg & Wartenberg 1991, Trumbo 2000). In Connecticut, of the hundreds of cancer cluster inquiries received over the years, only a small handful have resulted in closer study and none of them have been linked to a common environmental cause.



Are cancer clusters real?

There is no doubt that cancer clusters are a real phenomenon. The study of clusters of cancer has sometimes led to advances in epidemiology. One of the first cancer cluster reports involved an epidemic of scrotal skin cancer among 18th century London chimney sweeps with high exposures to PAH chemicals in chimney soot (Aldrich & Sinks 2002). More recent cancer cluster studies also have been successful in explaining higher cancer rates for certain occupations such as mesothelioma among asbestos workers and hepatic angiosarcoma (a rare liver cancer) among workers exposed to vinyl chloride during PVC plastics manufacturing (Benowitz 2008). And when Boston area physicians noticed a cluster of a rare form of vaginal cancer among their patients in the 1970s and early 1980s, a cancer cluster study revealed a previously unknown and unsuspected cause of cancer (use of the drug DES to prevent premature labor in mothers of the women with cancer) (Robinson 2002). Finally, studies of familial cancer clustering has helped better define the genetic determinants of breast cancer (Bender et al. 1990). While there are indeed some examples of cancer cluster studies that have identified a common cause and have advanced scientific knowledge, the vast majority have not. A recent national review of cancer cluster investigations conducted over the past 20 years showed that extensive efforts to find environmental causes of community cancer clusters have not been successful (Goodman et al. 2012).

Notable Cancer Cluster Studies

The following summarize some of the particularly well known environmental cancer cluster studies. The outcomes of these studies may be surprising because common perceptions often differ from the facts.

Love Canal, NY: The Love Canal residential neighborhood in Niagara Falls NY was one of the first and most seriously contaminated hazardous waste sites in US history. Over 200 chemicals, primarily pesticides and chlorinated solvents, were buried and the land redeveloped with homes. After contamination was discovered in 1978, numerous cancer and non-cancer health studies were conducted among Love Canal residents. Results of these early studies were largely equivocal or contradictory, but follow-up periods were rather short. A study published in 2009 was the first to focus on long-term health effects (including cancer) of former Love Canal residents. Among the more than 6,000 former Love Canal residents, the 2009 study found no elevation in cancers, as compared with Niagara County or with New York State (Gensburg et al. 2009).

Hinkley, CA: In the 1950s and 1960s, the Pacific Gas and Electric company used chromium 6 (a carcinogen) to fight rust in its cooling towers, then stored the chromium-contaminated water in unlined ponds. Chromium 6 migrated into the groundwater used for drinking water by residents of the high desert community of Hinkley. A lawsuit against the company, settled in 1996, was made famous by the Hollywood movie "Erin Brockovich," but cancer surveys conducted by the state of California, beginning in 1995 and most recently updated in 2008, have found no elevations in cancer rates in Hinkley (California

Cancer Registry 2011).



Fallon, Churchill County, NV: In 2000, a health care provider notified public health officials of a cluster of childhood leukemias around the city of Fallon. Between 1997 and 2002, 16 children were diagnosed with leukemia; a rate 12 times higher than expected (Steinmaus et al. 2004). For comparison, in the preceding 20 years, there was only one childhood leukemia case among Churchill County residents. This cancer cluster is one of the largest pediatric leukemia clusters in US history (Rubin et al. 2007). The dramatic increase in leukemia cases in a short time period, and in a relatively small population, highlights the extremely unusual nature of this cancer cluster. Despite years of biologic and environmental testing and multiple epidemiological studies, no common cause has been identified to link these leukemia cases and no exposure consistent with leukemia risk has been identified in Fallon (Rubin et al. 2007).

Woburn, MA: In 1979, Woburn residents noticed a cluster of childhood leukemia cases. This prompted investigations which discovered that two public drinking water wells were contaminated with trichloroethylene (TCE) and other organic compounds (presumably originating from nearby former industrial sites). Between 1969 and 1986, 21 cases of childhood leukemia were diagnosed in Woburn. Early studies concluded that the childhood leukemia rate in Woburn was elevated (2.3 times above expected), but could not establish any environmental causes (MA DPH 1981). Later studies found potential associations between ingestion of contaminated drinking water and increased risk of childhood leukemia. However, not all of the leukemia cases could be explained by the contaminated wells because several cases occurred in children with no access to the wells. (ATSDR 1997). A case-control investigation conducted in 1997 found a higher risk of leukemia in children, but only in those exposed to TCE in utero (MA DPH 1997). All of the studies were limited by the small numbers of cases and the incomplete exposure information. Like Hinkley, Woburn was made famous by a movie depicting a lawsuit against the alleged polluters. While one of the

companies was found liable for the Woburn pollution, the case was settled before a legal decision was reached regarding the cause for the leukemia cases.



Tom's River/Dover Township, NJ: In the mid-1990s, Tom's River physicians noticed an increase in cancers among children from the area. When childhood cancer rates were examined, it was discovered that between 1979 and 1995, leukemia and brain/central nervous system cancers among young children (under age 5) were up to 11 times higher than expected in some census tracts (NJ DHSS 1997, NJ DHSS 2003). A case-control study looked at possible environmental exposures to explain the higher cancers. There is evidence of historic contamination by volatile organic compounds (VOCs) in some public drinking water wells. There is also a facility that emitted hazardous air pollutants; however, data on historic levels of air pollutants do not exist. The study found that for leukemia only, there was an association with prenatal exposure to some of the wells known to be contaminated with VOCs and with estimated prenatal exposure to contaminated air (NJ DHSS 2003).

Why are cancer clusters so difficult to prove and so hard to link with environmental causes?



First, most of the cancer clusters brought by citizens to the attention of public health agencies consist of many different cancers, with different etiologies that are unlikely to have a common cause. There is also our natural tendency to notice cases first, and then define a cluster boundary around the known cases, creating a potentially artificial cluster. A third problem is cancer's long latency period. Unlike infections or acute toxic reactions, the effect of a carcinogen in a community will not usually be seen for many years. In our highly mobile society, cancer patients who appear to be clustered geographically may not have lived in the area long enough for their cancers to have a common cause (Gawande, 1999). But probably the most important factor is that the development of cancer is a highly complex process. To produce a cancer cluster, a carcinogen must affect a huge number of cells in a huge number of people, over a long period of time. This may be possible in some industrial and medical settings but is extremely rare in most community settings. And even when people have received a heavy dose of a carcinogen and many cells have been damaged, not all will get cancer. After all, for reasons we do not fully understand, the majority of smokers do not get lung cancer (Beil, 2011).

What is the appropriate public health response to concerned citizens?

As public health professionals, we understand that the vast majority of cancer cluster reports are extremely unlikely to have a common environmental cause and do not need follow-up investigation. However, the general public is not likely to be reassured by complicated epidemiological or statistical arguments that deny the existence or importance of a cancer cluster. The perception of elevated cancer rates in a community is as important (or perhaps even more important) than whether a true cancer cluster exists.

Our first level of response should be to quickly and sensitively establish a rapport with the citizen. Research clearly shows that when trust is established, our risk communication messages will be better understood and accepted (Siegrist et al. 2001). The vast majority of cancer cluster calls can be resolved at initial contact. Four key messages to communicate at initial contact are the following:

- 1. Cancer is not one disease; different cancers have different causes and risk factors.
- 2. Cancer is very common, affecting 30% 50% of us in our lifetimes.
- 3. Age, family history and lifestyle factors (diet, exercise, obesity, alcohol, tobacco) are usually more important risk factors for cancer than environmental contamination.
- 4. It is very unlikely that a neighborhood experienced a common environmental exposure large enough to cause increased cancer.

In most cases, the concerned caller will realize that what seemed like a cancer cluster is not actually a true cluster.

Further investigation should only be considered when a cancer cluster report involves: (1) cancers of the same type (particularly if they are rare cancers); (2) cancers in numbers likely to reach statistical significance; (3) cancers diagnosed within a short time period, and; (4) the presence of a possible common environmental exposure.

The CT Tumor Registry can assist in identifying whether a particular cancer is considered rare and whether the numbers of cancers being reported appear to be statistically elevated. Further investigation might consist of calculating cancer incidence rates for a particular town using CT Tumor Registry data. However, cancer cluster inquiries almost always involve a geographic area of interest different from a town. For example, neighborhoods and schools are frequently a focus. Cancer rates cannot easily be calculated for geographic areas smaller than a town, particularly if accurate denominator population data are not available for that area or group.

Even though most cancer cluster calls will not result in further investigation, cancer cluster inquiries provide public health professionals with valuable opportunities to educate people about cancer and environmental exposures. We can also promote cancer prevention actions such as cancer screening and healthy lifestyle choices and environmental exposure prevention actions such as home radon testing, and private well water testing.

What Can Local Health Departments Do?

In many cases, a local health department will be able to resolve a cancer cluster inquiry during initial contact. The steps outlined below can be used as a guide.

- 1. Educate the caller using the 4 key messages listed in the previous section of this technical brief.
- 2. If the caller's cluster concern involves people diagnosed with the same cancer type, contact the CT Tumor Registry for information about the rarity of the particular cancer type and whether the number of cancers reported appears to be elevated.
- 3. Contact the Environmental Epidemiology and Occupational Health Program for information about possible common environmental exposures.
- 4. Be careful not to promise a cancer study or raise the caller's expectation that follow-up will find the cause for the cancer cluster.



Contact Information

CT Tumor Registry

Environmental Epidemiology and Occupational Health

860-509-7163

860-509-7740



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