

Cancer Cluster Concerns in West Virginia

Shawn Farley, MHA, CTR
Director

Office of Epidemiology and Prevention Services
National Program of Cancer Registries Program Review
April 24-25, 2019



Cancer Concern Challenges

- West Virginia is located within the Appalachian mountains with a population of 1.8 million.¹ It is made up of small communities isolated by terrain, making single digit counts of cancer in these communities seem significant.
- West Virginia's population has decreased over the past decade.² Population movement makes geocoding and tracking cancer concerns over time more challenging.
- Precise population counts and demographic profiles are not available for small communities, making mortality and incidence rates difficult to calculate (unknown error rate, no age-adjustment).
- The leading cause of death in West Virginia is cancer,³ unlike the nation which is currently heart disease.⁴
- West Virginia ranks the second highest in the nation in the prevalence of poor health behaviors, second highest for adult smoking, highest in obesity, and third highest for overall cancer prevalence.⁵
- Cancer facts from the cancer registry have not been well received in communities as emotions are high during public meetings.

How Do Cluster Concerns Start In West Virginia?

- Significantly high rates of a cancer in our annual burden report identified by the cancer registry epidemiologists.
- Inquiry about a cancer concern from a physician, citizen or citizen's group.
- Inquiry from a local politician.
- Notification from the state's Environmental Protection Agency (EPA).
- Notification from the Agency for Toxic Substances and Disease Registry (ATSDR) about an environmental concern or investigation in our state.
- All initial concerns are handled by the Epidemiologist of the Cancer Registry and treated initially as a data request. The Epidemiologist examines our data for unusual patterns.

Case One - Background

- A primary care physician reported a concern regarding five recent thyroid cancer cases she had diagnosed in her county.
- Registry was asked to investigate the possibility of a thyroid cancer cluster.

Case One – Registry Responsibilities

Steps in the investigation

- Reviewed literature of known risk factors and trends in thyroid cancer diagnosis and treatment.
- Contacted The Department of Health and Human Resources (DHHR) Office of Environmental Health Services (OEHS) to evaluate any known issues with iodine, radioactive waste or processing facilities, and radon gas.
- Geocoded patient residences and mapped results to look for spatial clustering.
- Examined target area case files to evaluate number of cases per year, patient age, tumor histology, stage at diagnosis and other factors.

Case One – Registry Responsibilities (cont'd)

Results of the investigation

- Most cases were early stage slow-growing thyroid cancers.
- No concentration of a single type of cancer, no unusual age distribution, and no group of rare cancers were found.
- Findings fit with recent research suggesting that, due to advanced imaging and fine needle biopsies, previously undetectable cancers are being identified and treated at a higher rate than in previous years.
- The physician was satisfied with the Registry's analysis.
- Other than contact with OEHS, this investigation was contained within the Registry.

Case Two - Background

- Ongoing concern dating back to the 1970s.
- Worksite with known polychlorinated biphenyl (PCB) contamination that was cleaned up from 1985 to 1987 but still has trace amounts of PCBs in recent sampling.
- Registry was asked to investigate occurrence of cancer.
- Investigation involved community groups, social media activists, local physicians, elected officials, traditional media, and the public.

Case Two – Registry Responsibilities

- Reviewed literature of known health effects of PCB exposure.
- Examined case files for unusual patterns.
- Provided education for citizens regarding:
 - The nature of cancer clusters.
 - Cancers known to be associated with PCB exposure.
 - The types of cancer found in the study area.
 - Ways to reduce exposure and risk for the cancers observed.
- Explained how cancer data is collected.

Case Two – Support Received

- National Program of Cancer Registries:
 - Offered to assist with conducting a formal cluster investigation if ordered by DHHR's Bureau for Public Health.
- ATSDR:
 - Provided background public assessment study (WVD981038300, 6/1/1993).
 - Provided a comprehensive summary of the known health effects of PCBs (ATSDR case studies in environmental medicine. PCBs toxicity. 2016).
 - With the EPA, conducted air, soil, and water sampling and analyses to determine current threat to public health.
 - Coordinated town hall meetings.
 - Provided educational materials on environmental health hazards.

Case Two – Support Challenges

- Defining the population of interest:
 - Primarily a worksite exposure.
 - Most sensitive epidemiologic study would compare on-site employees to non-employees.
 - Unable to obtain employment records from previous 50 years (SSN/DOB from Social Security Administration or from Internal Revenue Service for linkage with Registry records).
- Calculating accurate incidence and mortality rates:
 - For small areas such as zip codes, population estimates from the US Census Bureau lack precision.
 - Unable to age-adjust statistics since demographic profiles are not available below the county level.
 - Small case counts result in huge confidence intervals.

Case Two – Support Challenges (cont'd)

- Managing effective communication:
 - Need an experienced, forceful moderator to maintain control of community meetings.
 - Emotional and hostile audience resistant to facts and data.
- Limiting the scope of the discussion:
 - Audience was convinced there is a problem, and added new issues that pulled the discussion away from cancer cluster concern.
 - Skin lesions, miscarriages, cancer in animals, flooding, property values, construction projects, etc.
 - Registry could not respond to non-cancer issues, so audience dismissed the Registry's evaluation of the cancer threat.
- Political pressure can circumvent the preferred investigation protocol:
 - Initial investigation showed no cancer concern related to PCB exposure.
 - Investigation should have ended at that point.
 - Pressure from the public, media, and state government to keep looking for something.

Community Meeting Handout

West Virginia Division of Cancer Epidemiology

Steve Blankenship, MS, Epidemiologist, West Virginia Department of Health and Human Resources, Bureau for Public Health, Office of Epidemiology and Prevention Services, Division of Cancer Epidemiology
350 Capitol Street, Room 125, Charleston, WV 25301
Minden Open House, March 16 & 17, 2018

Cancer Registry Operations

Basic Operations

- Collects information on all reported cases of cancer among West Virginia residents, even if treated out-of-state
- Established by state law in 1992
- All hospitals, treatment facilities, diagnostic facilities, doctors, nurses, and other health practitioners are required to report cancer cases to the Registry
- Conducts case-finding at facilities – search records to identify cancer cases that may have been previously overlooked
- Operations are certified by the North American Association of Central Cancer Registries (NAACCR)
- Certified at the “gold” (highest) level of data completeness, timeliness, and quality every year since 1999

How are Cancer Registry data used?

- **Support cancer control and prevention**
 - Identify areas of high cancer incidence so additional screening and education can be directed to those areas
 - Provide data to legislators and other officials for planning and decision-making purposes
 - Provide data to civic groups in support of grant applications
 - Provide numbers to hospitals and healthcare organizations for planning and supporting patient care needs
 - Provide the public with detailed summaries of cancer in West Virginia
<http://www.dhhr.wv.gov/oeps/cancer/Documents/burdenreport2017.pdf>
- **Support approved research studies**
 - Provide data to evaluate the safety of medications
 - Provide data to assess the effects of lifestyle factors on the development of cancers
 - Provide data to assess potential cancer clusters

The West Virginia Cancer Registry does not conduct cancer cluster investigations. Our records are available, however, to any researcher approved by the West Virginia Cancer Advisory Committee, with the written consent of the individuals involved.

Cancer Clusters

- A greater than expected number of cancer cases that occur within a group of people in a geographic area over a period of time
- Clusters can happen randomly, with no identifiable cause or reason
- A suspected cluster is more likely to be a true cluster, rather than a chance-based cluster, if any of the following are seen:
 - A large number of cases of one type of cancer, rather than several types
 - A rare type of cancer
 - Cancers in a particular age group that is normally not prone to that type of cancer

PCBs and Cancer

- Polychlorinated biphenyls (PCBs) were present in insulating oils in electrical transformers manufactured and distributed at the former Equipment site
- PCBs are classified as a cancer-causing agent based on a consistent link between exposure to PCBs and melanoma skin cancer⁽¹⁾
- PCBs have sometimes been linked to liver, stomach, gallbladder, biliary tract, and thyroid cancer

Cancer in Minden

- A total of 81 cases of cancer were reported in the Minden zip code from 1993 through 2014⁽²⁾
- Of those 81 cases, 42% were respiratory cancers, and 15% were breast cancers, the two most common cancers diagnosed in West Virginia
- Neither lung nor breast cancer has been linked to PCB exposure in humans
- 1% of the cancers were skin cancers. Melanoma skin cancer is the primary cancer that has been positively linked to PCB exposure in humans
- No concentration of a single type of cancer, no groups of rare cancers, and no cancers in unusual age groups have been reported in Minden
- There has been no significant increase in the number of cancer cases per year in the Minden zip code from 1993 to 2014

See chart on back for more information.

Cancer Prevention

Lung Cancer

- Lung cancer is the most commonly diagnosed cancer in West Virginia, with more than 2,000 new cases diagnosed each year
- Lung cancer is the leading cause of cancer-related death in West Virginia, with nearly 1,500 deaths attributed to lung cancer each year
- Smoking is the number one risk factor for lung cancer
- Other significant risk factors include: second-hand smoke, working in and around coal mines, radon gas, and having a family history of lung cancer
- For those who are or who have been heavy smokers, talk with your doctor to see if you qualify for lung cancer screening
- Finding a problem early can increase treatment options, increase the chance of successful treatment, and improve your quality of life

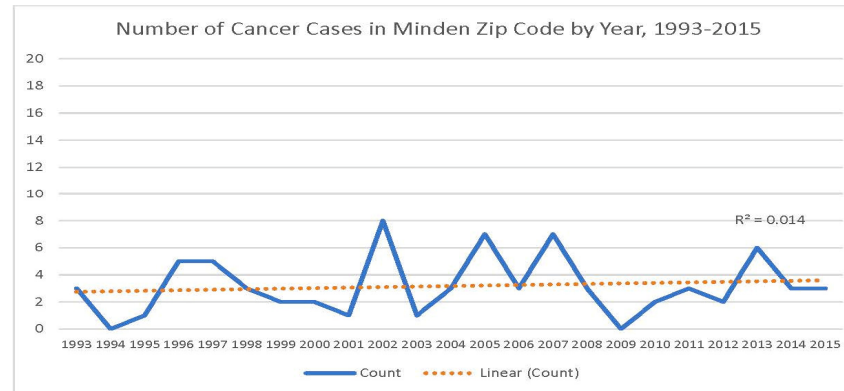
Breast Cancer

- Breast cancer is the most commonly diagnosed cancer among women in West Virginia, with more than 1,400 new cases each year
- Breast cancer is the second leading cause of cancer-related death in West Virginia women, with nearly 200 deaths attributed to breast cancer each year
- One in eight women will develop breast cancer in her lifetime
- Risk factors for breast cancer include: increasing age, having a family history of breast cancer, early menarche or late menopause, having dense breast tissue, long-term use of hormone replacement therapy, and genetic factors
- Women should talk with their doctors to discuss an appropriate screening schedule
- Screening saves lives, and finding the problem early is important
- Early detection can make treatment easier and quicker, increase the chance of successful treatment, and improve your quality of life

References

1. Agency for Toxic Substances and Disease Registry. Case Studies in Environmental Medicine. Polychlorinated Biphenyls (PCBs) Toxicity, 2014
2. West Virginia Cancer Registry, data from 1993 to 2014

Community Meeting Handout



There has been no significant increase in the cancers per year in Minden from 1993 to 2015.

Comparison of Cancer Rates in Fayette County to WV and US Rates, 2010-2014				
Cancer Site	Rank (Out of 55 counties)	Fayette County Rate/100,000	WV Rate	US Rate
ALL Sites	21	479.8	475.9	452.3
Breast	17	118.9	114.8	123.6
Colon & Rectum	20	50.1	46.6	39.8
Kidney & Renal Pelvis	25	18.3	18.1	16.2
Leukemia	13	17.3	14.3	13.7
Lung & Bronchus	11	91.5	80.4	61.5
Melanoma	40	15.6	20.7	20.6
Non-Hodgkin Lymphoma	32	17.6	18.6	19.0
Oral Cavity & Pharynx	10	16.0	12.7	11.5
Pancreas	47	7.9	11.7	12.7
Prostate	39	84.1	99.6	115.0
Thyroid	43	10.3	15.8	14.3
Urinary Bladder	41	20.8	23.4	20.5

Fayette County ranks 40th among WV counties in melanoma skin cancer rates (39 WV counties have higher melanoma rates than Fayette County). Melanoma is the cancer most closely associated with exposure to PCBs.

References

1. United States Census Bureau. Accessed at www.census.gov/quickfacts/wv on 3/15/2019 at 7:55 am.
2. Mckillop and M. Newman, D. (2018, June 20) retrieved from www.pewtrusts.org/research-and-analysis/articles/2018/06/20/years-of-slower-population-growth-persisted-in-2017?utm_campaign=governing&utm_source=twitter&utm_medium=social&utm_content=2017map
3. Centers for Disease Control and Prevention. Accessed at www.cdc.gov/nchs/pressroom/states/westvirginia/westvirginia.htm on 3/15/2019 at 8:40 am.
4. Centers for Disease Control and Prevention. Accessed at www.cdc.gov/nchs/fastats/leading-causes-of-death.htm on 3/15/2019 at 8:42 am.
5. Shanholtzer, B. Health Statistics Center. West Virginia Department of Health and Human Resources, Bureau for Public Health. (2017) West Virginia Behavioral Risk Factor Surveillance System Report 2016.

Contact



Shawn Farley, MHA, CTR

Director

West Virginia Department of Health and Human Resources

Bureau for Public Health

Office of Epidemiology and Prevention Services

Division of Cancer Epidemiology

350 Capitol Street, Room 125

Charleston, WV 25301

Phone: (304) 356-4953

Email: Shawn.O.Farley@wv.gov

Visit us on the Web:

www.cancerregistry.wv.gov

Funding:

Centers for Disease Control and Prevention #NU58DP006300-02-00