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Cancer cluster communications: bridging the gap between science and public perception

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CANCER CLUSTER COMMUNICATIONS: BRIDGING THE GAP BETWEEN SCIENCE AND PUBLIC PERCEPTION

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In response to the increasing request for cancer cluster investigations and the challenges in communicating the complexities of the studies and results, the author conducted case studies of childhood cancer cluster investigations in Dover Township, New Jersey and Fallon, Nevada to review state government communication and responses from residents. The purpose was to assess the residents' understanding and acceptance of the communication and to recommend guidelines for similar investigations based on lessons learned by officials and on recommendations by health risk communication experts in the public and private sectors. The study included content analyses of newspaper articles, intercept surveys, mail and e-mail surveys, and interviews with state officials, citizen committee leaders, and reporters.

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Challenges in Risk Communication

More than 15 million new cases of cancer have been diagnosed in America in the past decade with half of all men and one third of all women now living expected to contract it. As a result, especially with the aging "baby boomer" population, cancer will strike most American households. As more people develop cancer, or have loved ones diagnosed with the disease, there is increased fear along with public demand to understand what causes it and to eliminate any risk factors, especially environmental influences.

Difficulty of communicating cancer cluster information

Cancer "clusters," defined as a greater-than-expected number of cancer cases that occur within a group of people in a geographic area over a period of time, are often suspected when people report that several family members, friends, neighbors, or co-workers have been diagnosed with cancer. These clusters are reported to state and federal health agencies, which use statistical methods and cancer registry data to determine whether a greater-than-expected number of cancer cases have occurred. Public health agencies are challenged by communicating information about cancer clusters to the affected publics. One reason is due to the rapidly increasing number of public inquiries -- thousands of perceived cancer clusters are now being reported annually as residents, leery of pollution from waste dumping, spills, and chemical plants, etc., discover apparent clusters. More than 2,000 published newspaper articles from 1990 to 2000 contained the words "cancer cluster"(Sinks, 2001).

Reports are so numerous that experts have a name for false clusters: the "Texas sharpshooter fallacy." The term refers to a hypothetical rifleman who fires several shots at a barn wall, then draws a bull's eye around the shots. According to the U.S. Department of Health and Human Services (DHHS), state health departments now get at least 5,000 claims of cancer clusters a year with about 90 percent being dismissed. Most people are not aware of the pervasiveness of cancer, which includes more than 100 types with a wide variety of causes and interrelated risk factors.

Complexity of cancer risk communications

It is important to understand the complex nature of cancer that makes it inherently challenging to identify, interpret, and address a cancer cluster. There is no scientific consensus on how many cases it takes, over what period of time, and in what geographic area, to constitute a "true" cluster (Ohio Department of Health as cited in Ward, 1999). The time between exposure to a cancer-causing agent, or the existence of other risk factors, and the development of cancer can be decades; therefore, causes are difficult, and in most cases impossible, to identify. Even when a cluster is confirmed, investigators almost always are unable to determine the cause because cancer is usually the result of a combination of factors that interact in ways that are not yet fully understood. Although approximately 10 percent of cancer clusters have had an excess over the expected number of cancer cases, few have led to discoveries of preventable causes (Sinks, 2001). In Minnesota, for example, where more than a thousand cancer clusters were investigated between 1984 and 1995, the state epidemiologist was quoted in articles as saying that, as far as finding causes, most cancer cluster investigations are a waste of taxpayer dollars, but the problem is perception and politics, and officials must respond. "If you're a public

health official, try explaining why a dozen children with cancer in one neighborhood doesn't warrant investigation. And the cases that are investigated aren't even the best-grounded ones; they are the cases pushed by the media, enraged citizens or politicians" (Bender, 1990, cited in Gawande, 1999).

Public health agencies must deal with the emotional reaction of cancer victims and their families upon learning of cancer and their wanting to know who or what is to blame. People seek an answer to this usually unanswerable question. "Cancer clusters are one of the most frightening, frustrating situations a community can encounter. The families simply want to know what is killing their children and how to stop it from happening anymore, but these two questions are often answered last, if answered at all" (Newman, 2002).

As Aldrich and Sinks (2002) noted, "The media catches onto a story that evokes mystery and fear. Ancedotal hypotheses fan the flames of the story. Citizens become aware of a high number of cancers in their area and identify real or perceived environmental hazards in their neighborhood and want them eliminated" (p. 811). However, several studies, including a study by the American Council on Science and Health (2001) found no firm evidence that traces of industrial pollution diffused in the environment are causing cancer clusters. "For now, however, there is a substantial gap between scientific findings on this issue and public perceptions"(p. 20).

How is cluster information effectively communicated?

Research on cancer risk communication is relatively new and inconclusive. Researchers and government health agencies have stated that more research is needed, as well as more consistent implementation of risk communication guidelines. "There is

considerable unmet need in cancer risk communication for new knowledge and recommendations for best practices. Those professionals choosing to pursue this work can make a significant contribution to the field" (Kreuter, 1999, p. 32).

Similarly, the National Cancer Institute's (NCI) communication goals state the need for improved communication and research. The goals include: help people distinguish important from insignificant health risks and deal with contradictory health messages, provide accurate and balanced information, and narrow the gap between what is known about cancer communications and what is practiced. "To achieve these aims, more research is needed, and the cadre of health communications scientists and practitioners who can conduct communications research and apply the results must be expanded" (NCI 2002, Priority Plan, p. 9).

Public reaction to risk messages is coming under increasing study by communication, psychology, and social science experts. No consensus exists regarding the most effective way to provide people with risk information (Rothman, Kiviniemi, 1999).

Purpose

Scientists and communications experts studying the process of effective communication and its impact on health have produced theories of health communications, including those that focus on how people process health information and how they respond to cancer-related risks (NCI, 2002). "Despite our progress in refining health communications theories, however, major gaps remain in our understanding of how consumers use health information" (NCI, 2002, p. 2). In its 2002 priority plan, the NCI's communication goals also include helping people distinguish

important from insignificant health risks and deal with contradictory or inaccurate health messages.

The NCI, the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances Disease Registry (ATSDR) have developed communication guidelines and training programs to help state and local health practitioners reach their target audiences. The CDC's 1990 guidelines for risk communication of cluster investigations note that the risk must be put in perspective, "in a sensitive, non-condescending manner," through comparison with more familiar risks. The ATSDR's guidelines note the challenge of communicating the complexities and uncertainties of risk, and one of their primary rules is, "Get the receiver involved up front" (ATSDR, 1987).

To effectively educate the public in a cancer cluster area, this researcher reviews some of the positives and negatives in cancer cluster communications by public health agencies in two case studies. The researcher, a former public information officer for the New Jersey Department of Environmental Protection and current communication professional with a consulting firm, compared the New Jersey Department of Health and Senior Services' (NJDHSS) communications in the Toms River, Dover Township (Ocean County) childhood cancer cluster investigation and the Nevada Division of Health's (NDHS) communications in the Fallon (Churchill County) childhood leukemia cluster investigation.

This researcher looks at how communication influences residents' understanding, trust, and acceptance. This study tests three hypotheses.

H1: It is expected that, in the Toms River case, the public's initial "outrage," defined as a high level of public anger and fear, and mistrust of the health agencies when first learning of the elevated cancer rates, lessens over time as the agencies communicate the complexities and limitations of cancer cluster investigations, and gradually improve the residents' comfort level.

> Outrage has a much greater influence on citizens' reactions to a hazard than the scientifically calculated risk. Outrage is based on valid psychological needs that must be recognized and met before a mutually acceptable solution can be found. Officials rely on a technically based value system that does not recognize the basis of outrage. Thus conflict arises between officials and citizens in risk situations. (Walter, Kamrin and Katz, 2000, p. 3)

H2: It is expected that certain public relations strategies, such as citizen liaison committees, help to improve communication and acceptance of government studies in a cancer cluster area.

Successful risk communication depends on the ability of those who originate risk communications to understand and address audience members' perceptions of and feelings about the risk in question. Successful communication of risk information poses challenges not only for communications planning, but also for creating links between the public and the science underlying risk information (Van Nevel, 1999, p. 5).

H3: It is expected that there will be gaps of misunderstanding, frustration and dissatisfaction after the study results are communicated.

"Despite what we know about communication and cancer, there are still common misconceptions among the American public. Most believe: a mouse is a little human;

ANY risk that increases one's chance of death or disease in unacceptable, and the plural form of an anecdote is evidence" (Ratzan, 1999, p. 268). State and federal health departments continue to struggle with the fact that it's upsetting to the people of a community that science cannot rule out the possibility that a cancer cluster might be related to environmental pollutants but cannot prove that it is.

> Dealing with cluster investigations is a balance of science and public relations. On one hand, every cluster report must be taken seriously and pursued to the point where science and logic can determine that it would not be useful to pursue the matter further. On the other hand, both the actual experience in conducting cancer cluster investigations and an understanding of the laws of chance, tell us that the probability of identifying an addressable health hazard is very small. (Oregon State Cancer Registry Cancer Clusters Web site)

This paper will offer recommendations for communication practices to reduce citizen "outrage" and narrow the gap between the scientific realities of cancer cluster investigations and public perceptions.

The researcher selected the Dover Township and Fallon cluster cases because both received national media attention, and both are clusters of childhood cancers, which are more likely to have local environmental influences and have a better chance of helpful results from investigation. Since adult cancers usually have 20-30 years or more between exposures and diagnosis, and there are more variables with diet and lifestyle factors, cluster causes are harder to determine. Dover Township is one of a very few cluster cases where researchers could identify probable increased risk due to environmental factors. In the more recent Fallon, Nevada case of elevated childhood

leukemia, environmental influences also are expected by residents and are being investigated by the state and federal governments. In February 2003, final study results were released which did not show a link between environmental exposure and an increased risk of leukemia.

Delimitations

The study does not attempt to study all the psychological and sociological influences and differences among residents in a cancer cluster and how that affects their perception and reaction to health risk communication messages. The case study comparison includes a content analysis of major newspaper coverage but does not include a review of all stories in all media on the two cases because of the overabundance and repetition of information.

Procedure

This study procedure triangulates three primary research methods. One is a content analysis of related articles in primary daily newspapers covering Dover Township (*Asbury Park Press*) and Fallon (*The Reno Gazette-Journal* and *Las Vegas Sun*). The analysis compares positive and negative stories/comments and understanding and trust of the governments' studies and communications. Other research included in-depth interviews with key staff at NJDHHS, NDHS, the ATSDR, and the CDC, which assisted the states in their investigations and public meetings. The purpose of the interviews is to obtain information on lessons learned and recommendations for future communication models. The researcher also reviewed health risk communication guidance published by the federal government and specialists.

The researcher conducted intercept surveys with residents in Dover Township and interviewed members of the town's Citizens Action Committee on Childhood Cancer Cluster (CACCC). For Fallon, Nevada, the researcher sent similar surveys to residents via mail and email. Addresses were picked at random from the Fallon telephone directory.

The researcher used Excel spreadsheets software to tabulate the content analyses and surveys and to develop graphic illustrations of the results.

Terminology

Arsenic – A solid poisonous element that is commonly metallic gray and crystalline

Cancer - A group of more than 100 diseases characterized by the process of uncontrolled growth and the spread of abnormal cells. Gene mutations and other changes accumulate in cells over a period of time ranging from years to decades, depending on the type of cancer.

Cancer cluster – A greater-than-expected number of cancer cases that occurs within a group of people in a geographic area over a period of time.

Cancer incidence – The number of new cases reported

Carcinogen – A chemical or other substance determined to cause cancerous cells

Environment – Air, water and soil, as well as substances and conditions in the home

Epidemiology – Study of disease incidence in human populations

Leukemia – a disease of the body's blood forming organs
- Acute lymphocytic – leukemia of the lymphatic system cells
- Acute myelocytic – leukemia of nervous system cells

Texas sharpshooter fallacy – An analogy used by scientists comparing false clusters to a hypothetical rifleman who fires several shots at a barn wall, then draws a bull's eye around the shots.

Tungsten – a gray-white heavy metal resembling chromium used for electrical purposes and in hardening steel

Literature Review

There are two main categories of literature and research pertaining to cancer cluster risk communications. One focuses on cancer cluster investigations – the difficulties, controversies, and guidelines for responding to the increasing demand for more investigations relating to potential environmental causes. The second category focuses on health risk communication in general, the complexities, obstacles, and recommendations for increasing effectiveness. The author addresses each separately, as well as literature on the two case-study clusters in Dover Township and Fallon, Nevada.

Cancer cluster investigation literature and research

According to the National Cancer Institute (NCI) and others, scientists and residents often differ in their explanation for why cancer clusters occur. Scientists estimate that more than half of all cancers are due to lifestyle factors including cigarettes, heavy alcohol use, and diet. Residents tend to blame cancer clusters on pollution or radiation in an area, while scientists suggest that clusters are usually chance occurrences, un-related to any specific cause or exposure.

For example, in Pottstown, PA, a group of residents had pushed for a cancer cluster study in 2002, but then decided they wanted the grant money used instead to reduce nearby pollution from a landfill, chemical plant, and nuclear generation station. The Pennsylvania Department of Health will continue with its study, but the residents, as in other cluster areas many times, are dissatisfied with the lengthy time periods and inconclusive studies, wanting government to "prove" that the potential environmental hazards are not causing cancer, which is impossible because of the limits of science.

A deputy director of the CDC, David Fleming, testified on cancer clusters before the Senate Cancer Coalition in 2001, noting that random events often cluster by chance and statistical tests cannot separate observed cancer clusters caused by chance from those due to an unrecognized common cause. He said state and local agencies must have the ability to mobilize quickly to respond to a cancer cluster concern and to integrate information about environmental exposures with information about cancer cases and cancer registry data.

Fleming commented on the challenges of cluster investigations and the fact that the preventable causes of most cancers remain undiscovered.

> A public health system that can identify and respond to cancer cluster inquiries will enhance our ability to understand the complex nature of cancer. This will require partnership among the federal, state and local levels such that the system as a whole has adequate information about cancer in the form of cancer registries, adequate environmental health capacity, and the knowledge and skill to use these systems to respond to the public. Communities around the country should expect nothing less. (Fleming, 2001, p.5)

Studies of cancer clusters to identify an environmental cause of cancer in a selected neighborhood usually are not successful for many reasons. These include:

1. Neighborhood cancer clusters are defined by place of residence at time of diagnosis, not at place of exposure.
2. The studies have very limited methods for measuring exposure to known and suspected carcinogens.

3. Neighborhood investigations often include too few cases for a statistically significant study or do not have adequate control for confounding variables such as tobacco smoke exposure and other lifestyle variables.

The CDC notes that an additional challenge in investigating cancer clusters is the "unrealistic expectation placed upon public health officials to identify and remove the cause of each cancer cluster. In reality, 85 to 90 percent of evaluated cancer cluster inquiries do not find an excess number of cancer cases" (Sinks, 2001).

A report by the Massachusetts Institute of Technology (2001) concluded that millions of dollars are being wasted studying cancer clusters in areas of Massachusetts. In 2001, there were 174 studies underway or planned in the state to investigate possible connections between community cancer rates and suspected carcinogens in the environment (*Boston Globe*, April 9, 2001).

The CDC investigated 108 cancer clusters between 1961 and 1982, and found no clear cause for any cluster (Caldwell 1990). Nonetheless, the CDC and other federal agencies acknowledge that public concern about clusters and the need to investigate them warrants the development of uniform guidelines to help the states establish clear priorities and criteria for response. The CDC is currently updating and expanding its 1990 guidelines.

Difference in perception.

The term environment is often defined differently by the public and by scientists. The public refers to the environment as the air, water, and soil. Scientists have a much broader definition of environment including the influence of smoking, diet, alcohol use

and other lifestyle factors. Using the public's definition of environment, most scientists believe that the environment causes a relatively small proportion of all cancers. Films such as "Erin Brockovich" and "A Civil Action" lead the public to believe erroneously that the environment, defined as contaminated air, water or soil, is largely to blame for most cancer (Wright, 2001).

"A Civil Action" was based on a cancer cluster in Woburn, Massachusetts believed to be due to water contamination from past industrial waste dumping. Twenty cases of childhood leukemia were identified in the community between 1964 and 1983. The study revealed that the patients with leukemia were more likely to have used water from two municipal wells contaminated with possible cancer-causing chemicals.

The "Erin Brockovich" movie showed how Pacific Gas and Electric Co. was believed to have contaminated drinking water supplies in Hinkley, California with chromium-6, resulting in various illnesses and cancers. Investigation did not find evidence of a link to the diseases, however the power company paid a $333 million settlement, the largest ever in a direct-action lawsuit in U.S. history, without acknowledging any liability. Chromium-6 has been shown to increase risk of lung and sinus cancers among workers inhaling it over long periods of time, but has never been shown to be related to any other human cancer, or to be carcinogenic when dissolved in drinking water (American Council on Science and Health, 2002).

In April 2003, Brockovich filed suit on behalf of Beverly Hills High School graduates, alleging that oil-drilling rigs on campus resulted in air pollution that contributed to a higher than expected number of cancers among graduates. The city of Beverly Hills and the school district announced that they will investigate.

Other recent cancer cluster investigations that have received much media attention include the Long Island, New York, and Marin County, California breast cancer studies. The first part of the $30 million Long Island study, which resulted from public outcry and urging by local Congressional representatives, failed to show any connection between the disease and pesticides, and only very slight correlation between cancer rates and exposure to other pollutants such as car exhaust and cigarette smoke (NCI, 2002). According to newspaper reports, response from many of the residents was non-accepting. "They didn't find anything conclusive because in the scientific world it has to be exact, but they couldn't say that 100 percent there wasn't a link" (*New York Times*, August 11, 2002). Some residents who criticized the study said it failed to look at more relevant chemicals than long-banned pesticides, as well as at potential radiation exposure.

In Marin County, California, where breast cancer increased by 70 percent in the 1990s among women between ages 46 to 64, a member of a local breast cancer group remarked, "While most cancer researchers discount the role of the environment, that's about 95 percent of what people in the community talk about" (*MSNBC Health News*, November 1, 2002). Marin County women, who watch what they eat and drink, exercise and have relatively healthier lifestyles than many other areas, are baffled. State and federal agencies are investigating the Marin cancer cluster, and will study potential environmental causes, but they note that Marin has higher known risk factors for breast cancer, such as a greater percentage of older, more affluent white women, and more women who are childless or delayed childbearing. It is not known why these factors increase the risk of breast cancer (Northern California Cancer Center, 2002).

Nationally, breast cancer is the leading cause of cancer deaths among women and is increasing at a rate of 0.6 percent per year (NCI), and breast cancer organizations are requesting more funds for environmental link studies. While the NCI and others acknowledge that more study is needed, they note that breast cancer deaths, like many other cancers, will continue rising as the population ages. To improve tracking data, CDC has initiated a surveillance system to track cancer and identify chronic disease links to the environment with 20 states participating so far.

"Few would dispute that we should keep track of the hazards of pollutants in the environment, human exposures, and the resulting health outcomes—and that this information should be easily accessible to public health professionals, policy makers and the public. Yet even today we remain surprisingly in the dark about our nation's environmental health" (Trust for America's Health 2002). The CDC's new surveillance program, called the Environmental Public Health Tracking Network, will include a system for integrating the tracking of hazards, such as the amounts of toxic chemicals in the environment, with human exposures and health outcomes, such as cancer and trends (CDC 2002).

In summary, there are differences in perceptions among scientists and government health agency professionals and the general public on the pervasiveness of cancer and its potential causes. Part of this researcher's review included case studies of cancer cluster investigation communications in Toms River (Dover Township), New Jersey, and Fallon (Churchill County), Nevada. Below is a background summary of each case.

Dover Township Childhood Cancer Study Background

In 1995, New Jersey cancer registry information showed that the childhood cancer rate in Dover Township was higher than any other part of the state 90 children were diagnosed with cancer (leukemia, brain or central nervous system) between 1979 and 1991, 23 cases greater than expected and three to seven times higher than state and national averages. Dover Township residents learned this information from a March 1996 *Star Ledger* newspaper article that reported the nine-month-old statistics that had not been given to the public by the state or county health departments.

The state health department had sent a letter to the ATSDR in August 1995 stating that the leukemia numbers were not statistically significant, and while the numbers for brain cancer and central nervous system were statistically significant, it was not possible to conduct studies to determine possible causes due to the small number of cases in the analysis. The letter noted that brain and central nervous system cancers were the second most common childhood cancers in New Jersey and the United States and that very little was known about the causes.

Initial "outrage" by citizens was very high in Dover Township because residents learned of the elevated cancer rates from the newspaper article and then learned that the state had copied the county health department on its letter to ATSDR but the county health officer did not share the information with the public. Parents protested in front of the county health office and, following several very negative newspaper articles about the state's lack of action, state health department and ATSDR officials agreed to meet with residents. At a pivotal town meeting, about 1,200 angry residents attended and for 90

minutes cancer victims and their families spoke about their loss of confidence in government.

Officials agreed to conduct a study and proposed a citizens' advisory committee to serve as liaison with various agencies and to help develop a plan. Due to a history of water contamination in the area from multiple sources, including a couple of Superfund sites, water sampling was expanded to search for possible causes.

The state and citizens' committee developed a Public Health Response Plan in June 1996 that mapped out the extent of research, possible exposure pathways, study time lines, and a plan to communicate results, with NJDHSS assuming responsibility for press releases and media communications. The plan included NJDHSS and ATSDR working with the county health department, citizens committee, county medical society, and school district to develop a health education program, with activities such as workshops and materials such as newsletters.

A six-year, $10-million study showed possible increased risks from past air and water contamination, but "no single risk factor evaluated appears to be solely responsible for the overall elevation of childhood cancer incidence (NJDHSS, December 17, 2001). The study found no environmental risk factors associated with brain and central nervous system cancer. Findings supported the theories that prenatal exposure to previously contaminated well water and Ciba-Geigy chemical plant's air emissions were risk factors for leukemia in female children, and that the mothers were more likely to have been exposed to air pollutants emitted from the Ciba-Geigy plant when it was in operation.

> While our findings suggest an association between these past exposures and childhood leukemia in females, this does not automatically and necessarily indicate a causal relationship. Due to the relatively low number of study subjects and other factors, chance cannot be excluded as a possible explanation for the findings. As important as what we found through this comprehensive study is what we didn't find. We found no consistent pattern of associations between the other environmental factors and any of the other cancer groupings evaluated. (NJDHSS, 2001, p. 2)

The report recommended that efforts continue to reduce or eliminate environmental exposures, NJDHSS continue tracking childhood cancer in Dover Township, and that the state and federal government continue educational efforts on cancer and environmental health.

An example of misunderstandings among the public of the study results was a University of Pennsylvania undergraduate thesis by an environmental studies student that stated,

> The epidemiologists and newspaper staff writers reporting on the case believe that our inability to find a causal link between cancer and environmental toxins in Toms River is reason to believe that those toxins do not represent a public health threat. In short, lack of data is being used as evidence of safety. (Cozzolino, 2002)

On the contrary, the study report and newspaper articles did not state that the inability to definitely determine a causal link was evidence of no public health threat. Both the main reporter for the story for the local newspaper and the research scientist for the case for the NJDHHS disputed this interpretation.

The history of the water contamination was that an independent trucker illegally disposed of 4,500 drums of hazardous waste from a Union Carbide Corporation plastics plant in 1971 and that contamination eventually reached a well field from which drinking water was drawn. In January 2002, after three years of mediation, a settlement of more than $13 million was reached with Ciba Geigy, Union Carbide and United Water Company of Toms River, and 69 families whose children had cancer. There was no admission of any liability by the companies. Linda Gillick, spokeswoman for the families and whose son has cancer, responded, "The numbers do not reflect, in any way, what the families and the children went through" (*Associated Press*, January 25, 2002).

Public pressure to conduct the Dover Township cancer cluster study also focused attention on the state cancer registry, which was found to be too out-of-date to be useful. The data bank has since been updated, and the state Assembly passed a law that set fines of up to $1,000 a day for medical personnel who fail to file timely reports of cancer cases. Another positive result of the study is that it prompted a reassessment of which chemicals should be regulated in drinking water. In addition, the state is now convening a cancer cluster "rapid response team" with Rutgers University's Environmental and Occupational Health Sciences Institute to work with a task force to develop a method to investigate future cancer clusters in New Jersey (*Asbury Park Press*, October 29, 2002).

Fallon, Nevada Childhood Leukemia Cancer Study Background

In February 2001, the health officer for the state of Nevada reported a statistically significant increase in the number of cases of childhood acute lymphocytic leukemia (ALL) in Churchill County. The state health department, which had started investigating ALL cases in 2000, asked the CDC to assist with an exposure study of selected

environmental contaminants. Local residents had expressed concern about pesticides applied to agricultural fields, higher than standard arsenic levels in drinking water, and jet fuel used at the Fallon Naval Air Station.

Between 1997 and 2002, 15 children had been diagnosed with ALL (three of whom have died) and one child had been diagnosed with acute myelogenous leukemia (AML). The expected rate was one case every five years per 100,000 children. CDC promised the community that results indicating community exposure to environmental chemicals would be released immediately rather than waiting until the entire study was complete. CDC established a field office and laboratory in Fallon and collected samples of 132 chemicals from more than 130 homes and 200 people. An expert committee comprising representatives from CDC, ATSDR, the U.S. Geological Survey, the Nevada State Health Division and the Nevada Department of Environmental Protection was convened to interpret analytical results and inform Nevada's state epidemiologist when elevated levels of environmental contaminants were found in any samples. The CDC's National Center for Environmental Health's Associate Director for Science, Thomas Sinks, said, "The successful collaboration in Fallon involves multiple departments within the state, the federal government and academic institutions. Representatives of the Fallon Naval Air Station have also volunteered their complete cooperation in the investigation"(Sinks, 2001, p.4).

In May, 2002, the Fallon case was part of the TV broadcast, *NOW with Bill Moyers*, entitled "Kids and Chemicals: A Special Report on the Scientific Search for Answers about how Environmental Toxins Affect America's Children." Dr. Richard Jackson, the director of the National Center for Environmental Health, explained how

research on cancer clusters once focused mainly on gathering environmental samples because investigators didn't have tools sensitive enough to measure which toxins had been absorbed. For the Fallon study, CDC and state health department research scientists used the latest instruments for sophisticated blood and urine analysis to test for minute traces of toxins in the bodies of the sick children and their families.

Preliminary results released in August 2002 showed the expected elevation for arsenic exposure, but levels did not differ between case and control families. While high levels of arsenic have been known to cause some types of cancer, previous studies have not linked arsenic with leukemia. The results also found unpredicted community-wide excess exposures to tungsten, a metal that has been mined in the area for years. Research on tungsten is very limited and its health effects and levels of concern are not known.

Families of the Fallon leukemia patients formed a group called Families in Search of Truth (FIST) in August 2002, saying they were dissatisfied with the pace and scope of the government investigation. Some members conducted a survey of about 3,000 residents to document various cancer cases, and are doing an independent probe into potential causes of the cluster. Members are skeptical of the government's determination that the jet fuel pipeline that runs through the town does not present a health threat to residents because it is based on data mostly provided by the pipeline company.

In February 2003, Nevada and the CDC released a final report that did not show a link between environmental exposure and an increased risk of leukemia. The results showed that levels of most substances analyzed in participant samples were not elevated compared with national estimates.

The following sections review existing research and guidelines on cancer and health risk communication.

Health Risk Communication Research

Although scientific advances continue to provide increasingly more precise information about the health risks that people face, there has been little consensus as to the most effective way to communicate this information. While there has been substantial scientific research on cancer cluster investigations, government recommendations on health communication are based on a combination of experience and limited scientific risk communication research.

To assess someone's understanding of a health hazard is to study the many beliefs that are relevant to decisions and behaviors concerning that hazard. Weinstein (1999) asserts that a basic set of essential points would include the identity and severity of the potential harm, the likelihood of harm under various circumstances, and the possibility and difficulty of reducing that harm. "Most current studies of hazard perception or knowledge fail to examine even this limited range of risk dimensions and use methodologies that are questionable" (Weinstein, 1999, p. 19).

Previous research has shown that when health risk information is conveyed in quantitative terms, individuals tend to construct their interpretations using ordinal or qualitative categories of risk. Marcus (1999) suggests that since individuals are prone to impose qualitative interpretations on quantitative risk information, health agency professionals should help individuals navigate through this process as part of risk communication intervention, and both quantitative and qualitative descriptions of risk should be presented to subjects. Marcus concludes that more research is needed to

identify optimal strategies for integrating both quantitative and qualitative presentations of risk into risk communication interventions. "The field of risk communication would clearly benefit from more research on how best to convey risk information to specific target audiences, using both visual and text formats" (Marcus, 1999, p. 38).

When communication fails, it is often not due to the receiver but rather that the communicators have failed to understand their audience. Fischhoff (1999) notes that, "The transmitter repeats what the receivers know and neglect what they do not. They use jargon or loaded language. They speak before they listen and undermine their credibility" (p. 12). Fischhoff advises the following:

> Figure out what facts have the greatest value to the audience; then relay those facts clearly. Cancer risk communication is not just about the facts. The interpretation of a message may cause and be affected by powerful emotions. The hope is to get the information part right. Doing so allows people to be as cognitive as they want to be in their decision-making. It may encourage them to think more before they act, by making thought seem more tractable. Just as undue emotion can swamp cognition, ineffective cognition can generate emotion--as people despair of thinking their way through to answering their problems. (Fischhoff, 1999, p. 12)

To improve cancer risk communication, Fischhoff recommends a formal set of procedures for capturing and comparing expert conceptions (an expert model) and target audience conceptions (a mental model) of the risk at issue. After these conceptions have been formalized, a research-based process is used to determine which elements of the

expert model most effectively improve the target audience's understanding of the risk. "Whereas the skills to conduct these procedures may be stock in trade for risk and decision scientists, they are unknown to the majority of health and risk communication planners" (Fischhoff, 1999). He suggests that messages should focus on the most critical facts that have yet to be understood; then those facts need to be transmitted in a credible, comprehensible way. Accomplishing these goals requires an analysis of which facts are most worth knowing and an analysis of what people currently believe.

Maibach (1999) notes that there are two distinct objectives for communicating cancer risk information: enabling audience members to make informed decisions and persuading audience members to adopt a specific belief or behavior. "The criteria for judging effectiveness must vary according to the objective of the risk communication program" (Maibach, 1999, p. 14). He believes Fischhoff's formalized approach to assessment and communication planning has the potential to improve the practice and evaluation of risk communication.

According to Rothman and Kiviniemi (1999), new intervention studies are needed that will allow investigators to assess directly the relative impact of different risk communication strategies. Investigators need to determine not only what strategies are effective but also why they are effective. They believe that intervention approaches that help people understand how a health problem could develop (its antecedents) and recognize what could happen to them (its consequences) offer the most effective way to communicate health risk information. "Substantial progress in our ability to transfer successful interventions across both different health domains and different participant

populations will come only after we have developed a more precise understanding of how people process and utilize health risk information" (Rothman, Kiviniemi, 1999, p. 49).

Ratzan (1999) notes that four predominant risk communication strategies have emerged for persuading the public to make effective health decisions -- public relations, advocacy, negotiation, and social marketing. Public relations strategies can be used to advance discussion of the need to understand risk as it relates to cancer. "Such a public literacy on cancer risk could provide a necessary basis for informed decision-making, understanding of bias and levels of evidence, and associations between risk factors and disease, statistics, probabilities, and critical thinking skills" (Ratzan, 1999, p. 268).

Public health professionals have asserted that the importance of effective health risk communication should not be underestimated. For example, in testimony before the Senate Cancer Coalition in June 2001, an NCI director stated that,

> At no time in history has the pace of scientific discovery about cancer and its causes exceeded what we are experiencing today. Likewise, never has it been so easy for so many people to have access to such a vast wealth of information. Effective communication empowers people to make informed cancer-related decisions and to engage in behaviors that will improve their health. Few other initiatives have the potential to simultaneously improve health outcomes, decrease health care costs, and enhance community satisfaction. (Hoover, 2001)

An increase in public awareness of environmental health issues is key to achieving federal health agencies' goal of "Promoting health for all through a healthy environment." Education at all levels is a cornerstone of broad prevention efforts

(Healthy People 2010, 2000, p.9). DHHS's stated health objectives for the nation in *Healthy People 2010* contain separate objectives for health communication for the first time.

> Substantial barriers still prevent major segments of the population from seeking and using cancer information. Some people continue to lack access to the array of communications media. Others are faced with content that is unintelligible to them (in the wrong language or language that is too complex), culturally inappropriate or simply ineffective. (Hoover, 2001, p. 6)

People need a better understanding that cancer takes many different forms, that each form has different risk factors, and that each form often involves a combination of risk factors. Diseases such as cancer raise fear and other emotions that increase the difficulty of communicating complex, technical health risk information (Hoover, 2001).

The National Academy of Sciences, in its recent assessment of health communication strategies, noted that public health communication needs contributions from many disciplines.

> Public health communication requires theories about behavior and behavior change; deep understanding of audiences, their cultural experience, and their social and structural circumstances; and understanding of the health infrastructure around the health concern and its medical nature. Increasingly, public health communication requires technical expertise with new technologies and medical knowledge about health problems. Some programs also need the expertise of

marketers, and others need informatics expertise. (National Academy of Sciences, 2002, p. 10)

In summary, cancer risk communication is difficult. People are imperfect and their knowledge of the relevant science is often fragmented and inaccurate. There is no consensus on how to best communicate complicated health risk information, but careful planning of health communication programs is essential to avoid alienating the public and to encourage the potential for success.

Government Public Relations Guidelines

The NCI has created three Centers of Excellence in Cancer Communications Research to accelerate advances in cancer communications knowledge. Interdisciplinary teams of researchers will develop, implement and evaluate strategies to improve both access to cancer information and its efficacy and dissemination. The intent is to learn how to help people distinguish important from insignificant health risks and deal with contradictory or inaccurate health messages so they can make informed choices.

The NCI recommends six planning stages for health care communicators in its guide, "Making Health Communications Programs Work": Planning and Strategy, Selecting Channels and Materials, Developing Materials and Pre-testing, Implementing Your Program, Assessing Effectiveness, and Feedback and Refine Program. The guide recognizes that all of the steps may not be feasible in every case and recommends that professionals use their best judgment in applying the strategies. "Successful health communication programs involve more than the production of messages and materials. They use research-based strategies to shape the products and determine the channels that deliver them to the right intended audiences" (NCI, 2002, page 2).

NCI's guide notes that communication can affect multiple types of change among individuals, organizations and communities but also notes its limitations.

> Communication cannot be equally effective in addressing all issues or relaying all messages because the topic or suggested behavior change may be complex, because the intended audience may have preconceptions about the topic or message sender, or because the topic may be controversial. (NCI, p. 3)

The communications plan includes establishing an Office of Education within NCI's Communications Division, enhancing online capabilities and interactive web sites, maximizing emerging technologies, helping people navigate through NCI's communications structure, improving alternative communication tools for underserved populations without Internet access, and increasing partnerships with outside organizations.

Part of NCI's 2002 priority plan includes a communications segment outlining its goal to improve people's understanding of cancer and therefore, to empower them to make informed decisions. Despite progress in refining health communications, gaps remain in the understanding of how consumers use health information (NCI, 2002).

The ATSDR's Primer on Health Risk Communication Principles and Practices advises health agency professionals to recognize that people's feelings are a legitimate aspect of environmental health issues and that such concerns may convey valuable information. The guidelines also recommend providing alternatives to public hearings such as smaller, more informal meetings.

> Citizen involvement is important because (a) people are entitled to make decisions about issues that directly affect their lives; (b) input from the

> community can help agencies make better decisions; (c) involvement in the process leads to greater understanding of and more appropriate reaction to a particular risk; (d) those who are affected by a problem bring different variables to the problem-solving equation; and (e) cooperation increases credibility. (Chess et al. 1988, as cited in ATSDR's primer)

The State of Minnesota, for example, has improved its public-response strategies and education so that it has not needed to conduct as many formal, and very expensive, cluster investigations (Gawande, 1999). That strategy, along with federal health agencies' strategies, includes the very important first step of getting the affected public involved up front.

According to Covello (1992), as cited in the ATSDR primer, public assessment of how much agency representatives can be trusted and believed is based upon four factors:

Empathy and caring;

Competence and expertise;

Honesty and openness;

Dedication and commitment.

The ATSDR's risk communication primer lists some myths and recommended actions from Chess et al. (1988) including the following:

Myth: Telling the public about a risk is more likely to unduly alarm people than keeping quiet.

Action: Decrease potential for alarm by giving people a chance to express their concerns.

Myth: We shouldn't go to the public until we have solutions to environmental health problems.

Action: Release and discuss information about risk management options and involve communities in strategies in which they have a stake.

Myth: Communication is less important than education. If people knew the true risks, they would accept them.

Action: Pay as much attention to your process for dealing with people as you do to explaining the data.

Myth: These issues are too difficult for the public to understand.

Action: Provide the public with information. Listen to community concerns. Involve staff with diverse backgrounds in developing policy.

Myth: If we give them an inch, they'll take a mile.

Action: If you listen to people when they are asking for inches, they are less likely to demand miles. Avoid the battleground. Involve people early and often.

Myth: If we listen to the public, we will devote scarce resources to issues that are not a great threat to public health.

Action: Listen early to avoid controversy and the potential for disproportionate attention to lesser issues.

The primer also recommends using Covello and Allen's (1988) seven cardinal rules of risk communication:

1. **Accept and involve the public as a partner.** The goal is to produce an informed public, not to defuse public concerns or replace actions.
2. **Plan carefully and evaluate your efforts.** Different goals, audiences, and media require different actions.
3. **Listen to the public's specific concerns.** People often care more about trust, credibility, competence, fairness, and empathy than about statistics and details.
4. **Be honest, frank and open.** Trust and credibility are difficult to obtain; once lost, they are almost impossible to regain.
5. **Work with other credible sources.** Conflicts and disagreements among organizations make communication with the public much more difficult.
6. **Meet the needs of the media.** The media are usually more interested in politics than risk, simplicity than complexity, danger than safety.
7. **Speak clearly and with compassion.** Never let your efforts prevent your acknowledging the tragedy of an illness or death. People can understand risk information, but they may still not agree with you; some people will not be satisfied.

In addition, the ATSDR has a Public Health Assessment Guidance Manual that includes an appendix on Guidelines for Effective Communication. Recommendations include: "active listening" to listen compassionately and then be "responsive, direct and

empathetic" (ATSDR, 2002). A list of recommended health risk communication resources is included in Appendix E.

The CDC's 1990 guidelines for investigating cancer clusters include a brief section on risk communication, which notes that investigators need to be responsive to the fact that a perceived problem must be resolved responsibly and sympathetically, even if no community health cluster exists. The guidelines acknowledge that the risk perceived by the community does not necessarily parallel the risk estimates produced by science due to other influencing factors. These include: whether acceptance of the risk is voluntary or imposed, the degree of control the community has over the source, the degree to which the source is comprehended, and the potential for adverse social and economic ramifications. The CDC is currently updating and expanding the 1990 guidelines, and has established a single point of contact through which cancer cluster inquiries flow as part of its efforts for consistent and effective communications.

In addition, CDC's Office of Communications has guidelines for assisting public health professionals in communications planning. The guidelines are available on its website and through workshops and an interactive CD, CDCynergy (2001), that gives a step-by-step framework and resources. The primary six steps highlighted in CDCynergy are:

- Determine and define the health problem
- Analyze the problem (Direct and indirect causes, How to intervene)
- Identify and profile audiences
- Develop communication strategies
- Test, develop and select strategies

- Develop an evaluation plan
- Launch plan and gather feedback

In summary, to be effective, health communication programs must be based on an understanding of the needs and perceptions of the target audiences.

Media Involvement.

The "Journalist's Handbook on Environmental Risk Assessment" notes that risk comparisons that contrast an involuntary risk with a voluntary one (chemical plant emissions to smoking) typically generate anger rather than understanding (Walter, Kamrin, Katz, 2000). The authors state that the most useful risk comparisons compare similar risks, compare risks with alternatives, or compare risks with benefits; e.g., comparison of the level of a substance in a suspected contaminated area to natural background levels or to regulatory standards. Concentration analogies (i.e., 1 part per million = 1 drop of gas in an auto gas tank), like risk comparisons, can cause anger if used merely to minimize the magnitude of the risk. Analogies should be accompanied by information on the concentration's significance to human health and the environment.

Many risk communication specialists believe that people's tendency to overestimate sudden, imposed risk and underestimate chronic or lifestyle-imposed risks is reinforced by the more extensive media coverage of accidents and pollution than of chronic situations. These specialists try to encourage reporters to be persistent in their coverage of the chronic risks that represent more than half of all cancers, such as diet and lifestyle or home contaminants (Walter, Kamrin, Katz, 2000).

Media tend to simplify complex, technical explanations, thereby losing some distinctions or qualifications. Thus, communicators must present messages most likely to

be transmitted without confusion by stressing key points, providing background necessary for understanding, and being straightforward regarding what is fact, what is speculation, and what is not known. Of course, even when these steps are followed, media that have not been closely covering a study sometimes oversimplify and paraphrase study findings that concluded a certain contaminant may have increased a risk factor to stating that the study determined the contaminant was found to be the cause of the cancer.

Recommendations from the Institute of Medicine's 2002 report, "The Future of the Public's Health in the 21st Century," include: Health officials and journalists should engage in ongoing dialogue to enhance the role of the media in protecting the public's health.

Ratzan suggests that health agencies and others should set a leadership agenda for communicating health risk issues. "This is where highly credible organizations such as the NCI, our professional societies and associations, and our universities could be most powerful by educating the media, and thereby educating the public, to be more health literate with appropriate expectations" (Ratzan, 1998, p. 270). The new media is providing an additional channel to advance understanding of health and cancer issues among the public. New technologies give more opportunity for influencing traditional media and creating new delivery systems that have the potential to target audiences.

Summary

The overall goal of cancer and health communication is the ethical employment of persuasive means for effective health decision-making. It means getting the right message to the right people with the intended effect. Multi-channeled communication is needed

that is open, often, and ongoing to reach the intended target audiences effectively. The integrity and credibility of the source of communication is the most important factor in building trust, relationships, and success of the communication act (Ratzan, 1998).

This researcher will focus on three methods to test the hypotheses outlined in Chapter 1 relating to certain aspects of effective health risk communication. The first is a content analysis of the primary newspaper coverage of state government communications in two case studies of cancer cluster investigation in Dover Township, New Jersey, and Fallon, Nevada. The second is interviews with the state health department officials primarily responsible for the cluster investigation communications and leaders of the citizen liaison committees and local reporters. The third method is intercept and e-mail surveys with residents in the cluster study areas as a qualitative support of results from the other research.

Study Design and Method

This study design triangulated three primary research methods using a mixed-method approach of combining qualitative and quantitative data. The quantitative research included a content analysis of newspaper articles and a Likert-scale intercept survey of residents. The qualitative research included in-depth interviews with key staff in the state health departments, as well as federal government and citizen committee representatives, and an environmental biologist who has been leading college student projects regarding the Dover Township case.

Content Analysis

The content analysis consisted of articles about the cancer cluster investigations in primary daily newspapers covering Dover Township, the *Asbury Park Press*, and Fallon, *The Reno Gazette-Journal*. The analysis reviewed articles from the time when news of states' awareness of the elevated cancer rates was first published until the final results of the states' main studies were made public. For Dover Township, those dates were from March 1996 through January 2003. For Fallon, the dates were from July 2000 through February 2003. The review looked at the articles' tone and comments about the lead agencies for the investigations, the New Jersey Department of Health and Senior Services, and the Nevada Division of Health. The frequency of primarily positive, negative or neutral articles was coded and tabulated. Newspaper articles about the investigations that did not discuss the state agencies were not included in the coding.

The purpose of the analysis was to assess the public's apparent understanding and trust, or lack thereof, of the governments' studies and communications. The review also was designed to test the three hypotheses noted in Chapter 1 that the public's initial

outrage would lessen over time as communication increased, that public relations strategies would help to mitigate the dissatisfaction of residents, and that there would still be some misunderstanding and frustration after the final study results were communicated.

Between 40 and 50 articles from each of the two newspapers were included in the tabulation. The articles from the *Asbury Park Press* were obtained online through the TEACH (Toxic Environment Affects Children's Health) web site archive resource. TEACH is a non-profit group comprised of approximately 60 families affected by the childhood cancers. The articles from the *Reno Gazette Journal* were obtained online through the newspaper's archives. The frequency of positive and negative articles at the start of the cancer cluster news was then compared to the frequency of positive and negative articles at the end of the study when results were announced to determine whether the number of negative articles had decreased or the number of positive articles had increased. The purpose was to test the first hypothesis that the public's outrage would lessen over time as the state agencies' communications increased.

Intercept Surveys

The researcher also attended public meetings and conducted intercept surveys with residents in Dover Township and interviewed members of the town's Citizens Action Committee on Childhood Cancer Cluster (CACCC). The intercept survey consisted of five Likert-scale questions designed to assess the residents' feelings at the start of the cancer cluster news and their opinions of the effectiveness of the state health department's communications initially, compared to the end when results were announced (See Appendices A and B for survey instruments). The survey asked residents

their reaction upon hearing about the area's elevated cancer rates, their opinion of the state's communications initially versus at the end, the importance of the citizens committee in improving the state's credibility, and their understanding of the study results.

The survey was conducted on January 13, 2003. Half of the surveys were conducted at random at the Ocean County Mall, and half were conducted at the CACCC public meeting on that date after the state health department discussed the final study results. Half of the 26 survey respondents were male and half were female.

As noted in the delimitations in the Introduction, the researcher acknowledges that the number of completed surveys is not a statistically significant sample size for the Dover Township population. The purpose of the intercept survey was to serve as a qualitative support of the content analysis and in-depth interview research methods.

Interviews

Other research included interviews with citizen committee representatives and key staff at the New Jersey and Nevada state health departments on how communication strategies were developed and implemented and their assessment of effectiveness. The purpose of the interviews was to obtain information on lessons learned and recommendations for future communication models. The interview with Michael Berry, research scientist for the New Jersey Department of Health and Senior Services, was conducted in person on November 11, 2002 at the American Public Health Association (APHA) meeting in Philadelphia where he and a fellow researcher presented their findings on the Toms River childhood cancer study. The interview was continued with follow-up questions via email. In addition, the federal ATSDR representative for the

Toms River study, Director of Regional Operations Juan Reyes, was interviewed after the session for his opinion of the communication efforts. The interview with the chair of the CACCC, Linda Gillick, also was conducted at the APHA meeting, following her presentation as part of the panel and followed up with the survey questions at the January 13, 2003 public meeting.

The researcher also interviewed the head of Wagner College's Toms River Project, Dr. Donald Stearns, an environmental biologist who has been conducting class field projects on the cancer cluster case since 1999. Dr. Stearns and his associate, Jonathan Peters of Staten Island College of New York, have been conducting exploratory field trips with their undergraduate students and interviewing members of the citizen committee, as well as representatives from state and federal agencies and local industry so that the students could interact with the community and acquire an understanding of the complexities and different perspectives involved in investigating the cluster and contamination.

For Fallon, this researcher interviewed the Nevada Division of Health's Public Information Officer Martha Framsted, who is the communications officer in charge of the state's childhood leukemia cluster investigation. She was interviewed via e-mail after the February 6, 2003 public meeting when study results were announced. Surveys were sent to some of the families of the study's childhood cancer patients whose names were found through newspaper articles. Surveys also were mailed to Fallon residents at random. The addresses were found through an online telephone directory search. Surveys also were sent to the Community United Response Team, which co-hosted the February 6 meeting, through Chairman Joe Cobery, the Director of Social Services for Churchill County.

Results and Data Analysis

Content Analyses

The results of the content analyses of the *Asbury Park Press* articles for the Dover Township cancer cluster case, and *The Reno Gazette Journal* and *Las Vegas Sun* articles for the Fallon case, supported the first hypothesis that the public's "outrage" when learning of high cancer rates lessens over time as agencies communicate the complexities of investigations.

There was a stronger correlation between the Toms River case study and the hypothesis than for Fallon. There was less initial outrage in Fallon, followed by a number of negative articles midway through the study, which then decreased after the study results were announced. The reasons for the differences will be explained in more detail in the next section, along with discussion of open-ended question comments and in-depth interview comments.

The content analysis of the *Asbury Park Press* articles showed, as expected, an initial prevalence of negative articles and few negative articles by the end of the study when results were announced (Table 1).

For tabulation and comparison purposes, the results of the Toms River cluster news articles were grouped in four, two-year segments, starting with 1996-1997 and ending with 2002-2003. A total of 55 articles were included in the analysis.

For the initial 1996-1997 period, there were more than a dozen negative articles involving the state health department and the cancer cluster in the *Asbury Park Press.* In the following two-year period (1998-1999), the frequency of negative articles decreased (4) and neutral articles increased (12). This trend in the decreasing frequency of negative

stories continued during the 2000-2001 and 2002-2003 periods. In 2000-2001, there were two negative articles, 14 neutral stories and two positive articles. In 2002-January 2003 when the final study results were announced, there was one negative, one neutral, and one positive article.

Table 1 shows 12 negative articles in the initial 1996-97 period. In the following two-year period (1998-1999), the frequency of negative articles decreased to four. This trend continued with two during 2000-2001, and one during 2002-2003.

Table 1.

Dover Township *Asbury Park Press* (March 1996-Jan.2003)

	1996-97		1998-99		2000-01		2002-03	
Articles	No.	%	No.	%	No.	%	No.	%
Positive	0	0	0	0	2	11	1	33
Negative	12	67	4	25	2	11	1	33
Neutral	6	33	12	75	14	78	1	33
Total	18		16		18		3	

For the Fallon case, the results of 55 articles about the cluster and the state health department in the *Reno Gazette Journal* and *Las Vegas Sun* were divided into the four years of the study. Beginning in July 2000, when the state announced it was investigating the elevated childhood leukemia rates, there were four neutral articles and no negative articles about the state health department's handling of the cancer cluster. (There were a few negative articles about Fallon having high arsenic levels in the drinking water and the EPA requiring the city to provide treatment.)

In 2001, there were 18 neutral articles, three negative stories and one positive article. In 2002, the frequency of negative articles increased to 11, while there were nine neutral stories and one positive article. In 2003, the frequency of negative articles decreased to four and there were four neutral stories.

Table 2 shows that while there were no initial negative articles about the state health department in the first year, there were three negative articles in the second year and 11 negative articles in 2002, which decreased to four in 2003.

Table 2.

Fallon *The Reno Gazette Journal* and *Las Vegas Sun* (July 2000-Feb. 2003)

	2000		2001		2002		2003	
Articles	No.	%	No.	%	No.	%	No.	%
Positive	0	**0**	1	**5**	1	**5**	0	**0**
Negative	0	**0**	3	**14**	11	**52**	4	**50**
Neutral	4	**100**	18	**82**	9	**43**	4	**50**
Total	4		22		21		8	

Survey Results

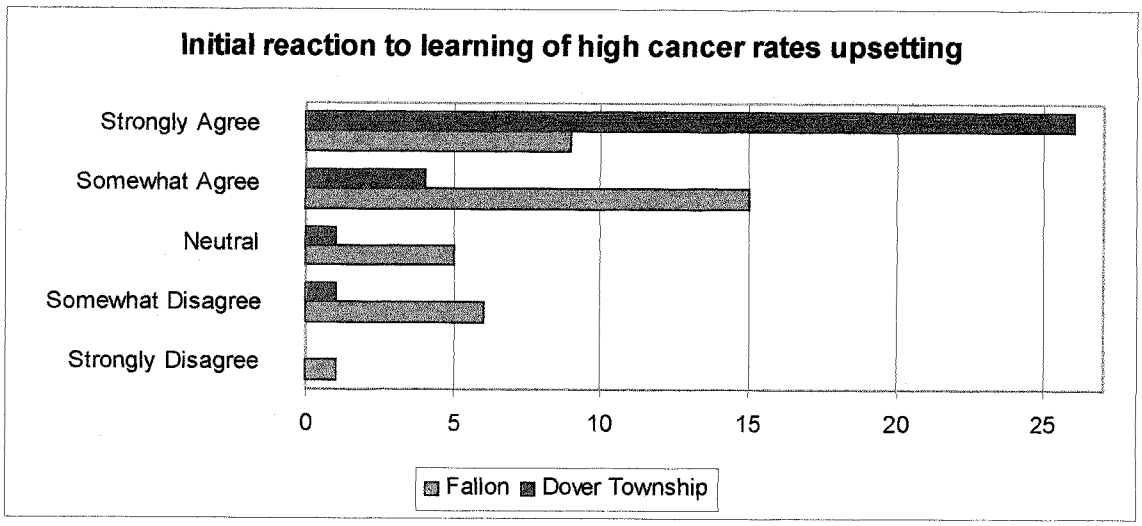
The results of the intercept survey of Dover Township residents and the mail and e-mail surveys of Fallon residents supported the first hypothesis, as well as the second and third hypotheses:

H2 – Public relations strategies, such as citizen involvement, help to mitigate the dissatisfaction of residents.

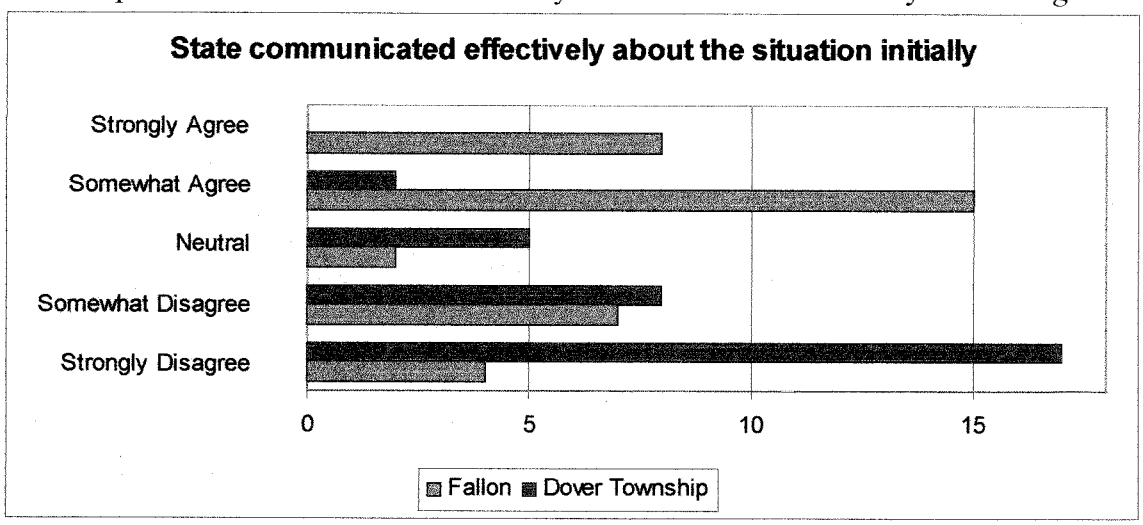
H3 – Gaps of misunderstanding and dissatisfaction will remain after the study results are communicated.

The results of the intercept survey of 32 Dover Township residents showed, as expected, that the large majority of residents surveyed were very upset upon first learning of the area's high childhood cancer rates. Thirty respondents said they either strongly or somewhat agreed that their reaction was upsetting, while only one responded that the news was not upsetting.

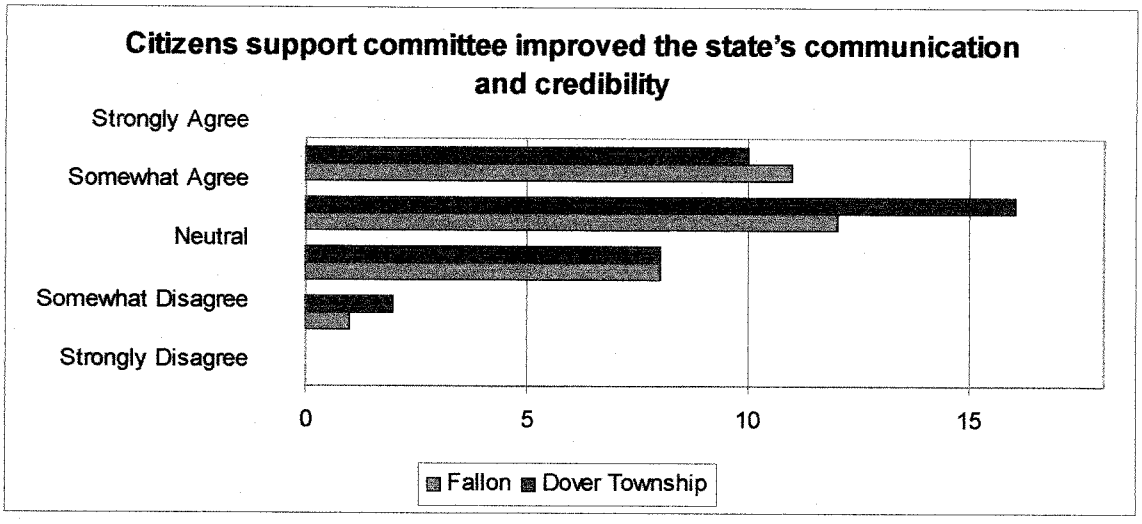
The random survey of Fallon residents via mail and e-mail provided 42 completed surveys, which showed a greater degree of varied opinions than in Toms River. The majority of respondents, 21, agreed that their initial reaction to learning of the high childhood cancer rates was upsetting, while six disagreed and five were neutral. *Figure 1*



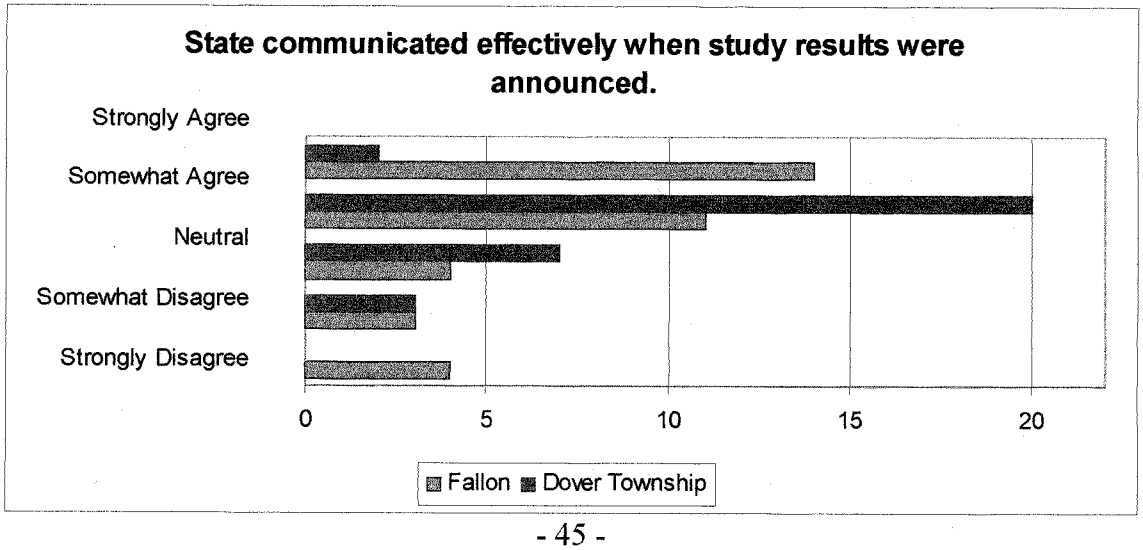
The majority of Fallon residents felt that the state communicated effectively about the situation initially, 22, while 8 disagreed and 2 were neutral. See Figure 2. The majority of Dover Township respondents disagreed with the statement that the state health department communicated effectively about the situation initially. *Figure 2*



As expected, the majority of Fallon respondents, 22, agreed that the citizens support committee improved the state's communication and credibility. Two disagreed and eight were neutral. The majority of Dover Township respondents agreed, as expected, with the statement that establishment of the citizens' liaison committee improved the state's credibility. One person disagreed and eight were neutral. *Figure 3*

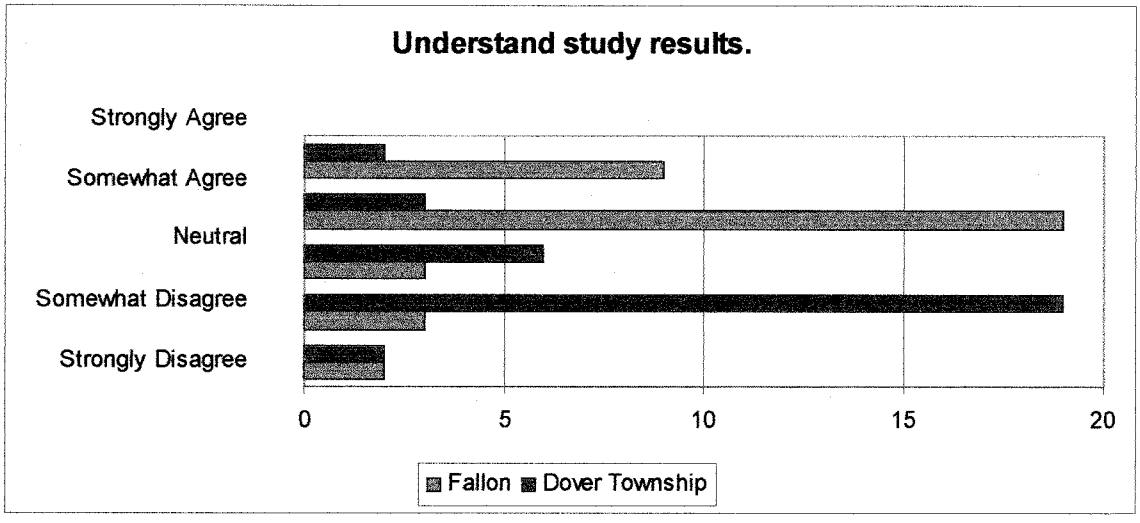


Also, 23 Fallon respondents agreed that the government communicated effectively when study results were announced, while five disagreed. The majority of Dover Township respondents, 22, agreed that the state health department communicated effectively by the end of the study. Only three disagreed. *Figure 4*



The majority of Fallon respondents also felt that they understood the study results, 25, while four disagreed and three were neutral. Figure 5 also shows that the majority of Dover Township respondents agreed that they understood the study results, 21, while five disagreed and six were neutral.

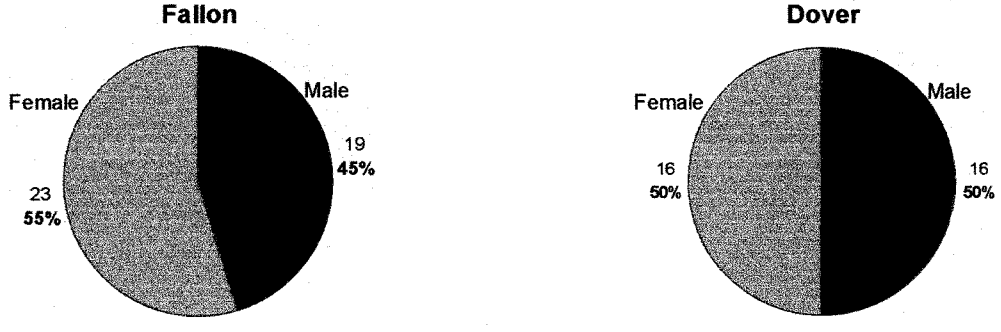
Figure 5



Because Fallon also has the dissident FIST citizens group, the Fallon survey asked residents' opinions on whether the FIST group was conducting valid investigations and making an important contribution to overall knowledge of circumstances in Churchill County. Respondents were split in their opinions on this, with 11 agreeing and 12 disagreeing. Nine were neutral.

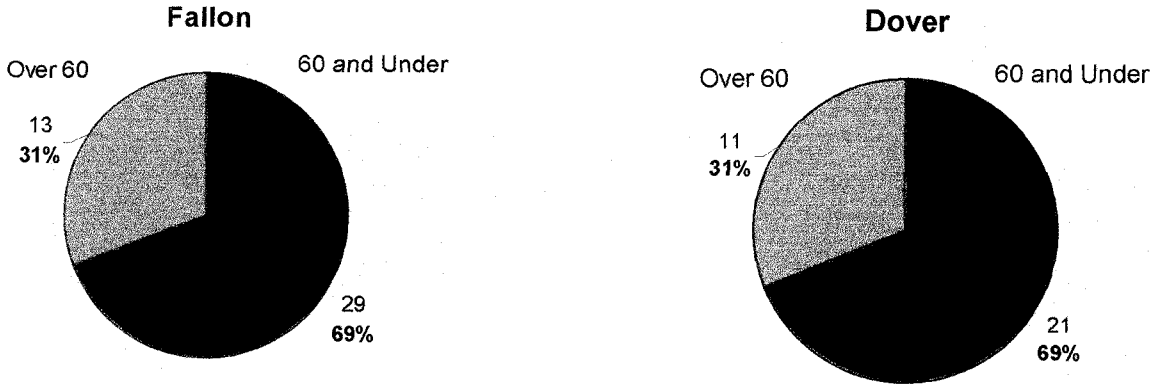
Twenty-three of the Fallon respondents were female and 19 were male. Figure 6 also shows that half of the Dover Township respondents were male and half were female.

Figure 6



Twenty-nine Fallon respondents were between the ages of 31 and 60, and 13 were age 61 or over. Figure 7 also shows that 22 Dover Township respondents were between the ages of 31-60 and 10 were age 61 or over.

Figure 7



Summary and Interpretation

Differences between Toms River and Fallon

The situation in Fallon differed from Toms River in that there was not the initial high outrage by residents or the negative media stories about the health department not announcing elevated cancer levels and not believing a study was feasible.

After the story of high childhood cancer rates in Toms River broke in the media in 1996, there was a flurry of negative media stories reflecting the "outrage" of victims' families that the state had not publicized the elevated cancer rates or initiated a study before the newspaper publicity. As evidenced in the *Asbury Park Press* articles and large crowd at the state's public meeting in Toms River in March 1996, the families and other residents were upset that the health department had not responded to victims' requests for a study or alerted the public to the high rates. The state had sent a letter about the elevated rates to the county health officer and to the ATSDR, but had stated that the size of the possible cluster and demographics were too small to do a meaningful study to determine if the higher rates were due to chance or an environmental cause.

In Fallon, however, the negative stories that appeared in the middle of the cluster study, in early 2002, primarily concerned the formation of a dissident group of victims' families who were not satisfied with the scope and pace of the government's study and started to conduct their own surveys. This group, called Families in Search of the Truth (FIST), was spearheaded by the father of one of the first girls to die of leukemia in the cluster study.

During 2002, there also were stories of a few doctors and independent researchers who faulted the thoroughness of the ongoing study, stating that more research was needed

on potential impacts from jet fuel at the Naval Air Station on DNA and effects of elevated levels of arsenic and tungsten in the water.

Instead of one unified citizen liaison committee such as the one that was formed at the onset in Toms River, a citizen support committee was developed in Fallon through the Churchill County Social Services Department in July 2001. This committee worked with victims' families and state and federal agencies to help address the emotional needs of the community, and to coordinate communication and services through planning similar to that following a toxicological disaster. The Community United Response Team (CURT) served in an advisory capacity and included members from hospitals, schools, municipal leaders, and the Naval Air Station. The social services director Joseph Cobery, who served as CURT chairman, noted that the committee participated in risk communication training with ASTDR, sponsored community education forums with the local college, and assessed the community's public health needs to develop a long-term strategy to address the significant issues. Cobery noted that CURT hopes to serve the community, and develop a blueprint for other communities to follow in the future.

Fallon Survey Respondent Comments

Approximately 30 percent of respondents to the Fallon survey included comments in a space provided at the end of the closed-end questions. The comments gave a good example of the divergent opinions and different perspectives. Several of the respondents stated that they thought the cluster is random and they did not believe a cause would ever be found. A few were concerned about the negative publicity from extensive media coverage hurting the town unnecessarily. For example, "While I understand the need to find answers, the economic impact to the community has been difficult. I hope that with

knowledge will come a balance of perspective on how to effectively deal with issues of this magnitude without destroying these communities."

On the other hand, one respondent said it was good that the citizens group helped to keep the subject in the public eye. "Publicity plays a big role in getting help in these situations." And while one respondent thought the FIST citizen committee was biased, another said the head of that committee showed courage to conduct his own cancer survey and that the independent scientist researching tungsten should be commended.

A few respondents felt that some leukemia cases in the cluster statistics should not have been included because the victims either had not lived in Fallon for many years, or had been sick prior to moving to Fallon and were diagnosed there. On the other side, two respondents felt that the cluster study should be broader and not limited to childhood leukemia. While one respondent believed the victims were mainly children of parents in the military and suspected jet fuel from the Naval Air Station, another stated that some citizens have been opposed to the naval base, and jet fuel was no more of a threat than the pesticides and other chemicals used by the area's agriculture industry. A military family responded that they were given a briefing on the cancer cluster investigation before accepting assignment in Fallon and decided that the study and information was acceptable.

A state assembly representative from Churchill County, who had encouraged the investigation, noted that the statistical odds of the large number of cases for the small population suggested the cluster was not random and more investigation of a cause was needed. "The fact that it (cause) hasn't been found doesn't mean we're not learning and it certainly doesn't mean we should stop trying to find the answers."

Interviews

Officials of the New Jersey Department of Health Senior Services (NJDHSS) and ATSDR were interviewed at the American Public Health Association conference on November 11, 2002 in Philadelphia. They participated in a panel discussion on the Dover Township childhood cancer investigation along with Linda Gillick, chair of the CACCC. The discussion also included communication aspects of the investigation and results.

State health officials and the ATSDR worked together to develop a Public Health Response Plan, with input from the citizens committee. They agreed to monthly meetings in Dover Township with the CACCC, which were open to the press and public. Local reporters covered the meetings regularly which increased their understanding of the complexities and nuances of the investigation, risk factors, and unknowns. Michael Berry of NJDHSS and Juan Reyes of ATSDR said the local press "became quite good" at reporting on issues and progress of the investigation. "You have to develop trust over time and maintain consistency; it can't be done overnight," Reyes said. When it came time to announce the draft results of the study, the two agencies coordinated a meeting with the victims' families to announce the results to them first and then informed other stakeholders. A press conference and televised public meeting followed. In addition to the regular media coverage, the entire meeting was broadcast over the local cable TV network.

Reyes said the Dover Township case is influencing other cases and serving as a model in public health practice. The investigation has sparked more research in prenatal exposures. "There is no magic formula for these cases, they are always a difficult task.

We always have to balance resources and the need to respond to concerns," he said. Reyes also noted the challenge of interpreting and communicating study findings due to different perspectives and expectations. "Peer review and stakeholder review help to increase credibility of results. He also noted the need to form partnerships. "You have to focus on what the needs of the community are. We got pediatricians to help deliver messages to the community."

Elizbeth Howze, director of ATSDR's Division of Health Education and Promotion, noted that health risk communication plans need to be flexible. "A community is not one audience but different segments," she said. She noted the difficulty in trying to address different public audiences such as business. "There tends to be an 'us versus them' mindset; ideally there wouldn't be," she said. Howze said the Fallon investigation started off well and the coordination of agencies has been going well.

Gillick said she felt that the committee had "a good working relationship with the state and ATSDR officials and the end result was quite good." She noted that the biggest effect of the cluster news initially was fear; realtors and some local officials and businesses were upset by the negative publicity and effect on property values. "There was big division for a long time in town between businesses and families," she said. Gillick noted that some of the national media coverage did not help such as when ESPN reported on Toms River winning the Little League Championship and saying, "They must be drinking the water." Now Dover Township is the most thoroughly investigated town; people don't want to move and it's hard to find a house to buy, she said.

One of Gillick's biggest challenges was "keeping everyone working together," including the various government level agencies and private companies. She felt the

CACCC was successful in several ways--being able to challenge proposals by the government and companies; hearing concerns of the community; and gathering data from all sources. "We wanted answers and the truth and to err on the side of caution," she said. Her advice to others in similar positions is to "stay calm, stay focused, and only give the facts." And her advice to government and industry officials is "we're not stupid, don't patronize us."

She noted that while there are still a lot of unanswered questions, the number of cancer cases has decreased and the committee will continue to watch the water companies and other industries in the area.

The notoriety of the Toms River case caught the attention of a environmental biology professor at Wagner College in Staten Island, NY, who started bringing students to Toms River in 1999 for a hands-on learning experience of the complexities of issues in cancer cluster investigations. Dr. Donald Stearns and his partner in the project, Dr. Jonathan Peters of the College of Staten Island, brought students on numerous field trips to Toms River where they interviewed victims and parents, members of the citizens committee, local and state officials, EPA officials and industry representatives. Stearns noted the residents' distrust of the government agencies and the local companies such as Ciba Geigy and United Water Co. He noted the pivotal roles that Gillick and Bruce Anderson of the CACCC played in spurring investigations and improved communications. "The people trust Linda Gillick as a watchdog for the community." While Stearns said that he doesn't think the science is capable yet of addressing the question of causation in cancer clusters, he felt that the government could have done a better job in communication by not "stepping around major issues with scientific jargon."

He noted that there are still many unknowns, such as the fact that there are hundreds of chemicals in water but drinking water is normally only tested for about 90. Stearns noted that New Jersey has one of the highest cancer rates in the country and recommended further environmental health education in local schools.

For Fallon, the public information officer for the Nevada Division of Health, Martha Framsted, responded to questions about the state's experience in that case with a list of recommendations that other states can follow in communicating similar investigations (see Appendix D). The recommendations follow accepted guidelines such as developing and implementing a risk communication plan, involving community liaison groups and including them in the investigative process, conducting town hall meetings, creating a web site, and establishing a toll-free community hotline. She also recommended involving local media as partners by explaining ground rules and confidentiality limitations early in the investigation, frequent communications and media briefings.

Reporter Interviews

Reporters knowledgeable in the Dover Township and Fallon cancer cluster stories also were asked to comment and to complete the survey. For the Fallon case, the reporter agreed that the state health department communicated effectively about the situation initially. The reporter disagreed that the state communicated effectively when the study results were announced in February 2003. The reporter felt that the state, to its credit, investigated right away without the denial typical in other cancer clusters in the U.S., but that it then became a "public relations cheerleader" for Fallon, focusing too much on just the good news and reassurances. The reporter agreed that the study results were

understood and that the CDC did its part of the job. However, the reporter felt that the ATSDR's separate 18-month study of the soil and water did not find meaningful information and that its report went too far to vindicate everyone while leaving out information that might indicate problems. The reporter believes that the FIST citizen committee is conducting valid investigations and making an important contribution to overall knowledge of circumstances in Fallon and Churchill County.

The primary reporter covering the Toms River story for the *Asbury Park Press* had similar responses to the survey as other respondents, stating that while the health department did not do a good job of communicating with residents about the cluster initially, the department greatly improved its communication with the residents through the citizens committee. The reporter felt that the health department was communicating effectively by the end of the study and that it conducted a credible study. The reporter noted, however, that the problems experienced at the start of the study led to the residents' general distrust, and it took years and "much wrangling for the government agencies to overcome that initial distrust."

Recommendations for Further Research

State and federal agencies are working to further develop and coordinate guidelines for both effective cancer cluster investigations and effective communication of those investigations. Health risk communication is a growing field of study with an increasing number of undergraduate and graduate degree programs in the U.S., as well as professional development opportunities through workshops, conferences and online continuing education courses.

The CDC, in cooperation with other agencies, is expected to publish an update of the 1990 Guidelines for Investigating Cancer Clusters later this year. Earlier this year, the CDC sponsored a workshop on this subject for healthcare professionals, and several states participated in sharing their experiences and programs. Goals for the future include further coordination among state and federal agencies for consistent, effective communication of potential clusters and health risks.

The author's recommendations for further research by health risk communication experts include additional formative research of initial awareness of issues and risks when news of a potential cluster first becomes public. Also, as the ATSDR education director noted, agencies naturally focus primarily on victims' families, but more could be done in reaching out to other audience segments such as the business community. As a few comments on the survey and some newspaper articles indicated, there were segments in both Toms River and Fallon that opposed the negative publicity of the cluster studies and complained of the economic impact on the communities while causes would probably never be found. Research into all the primary segments of a cluster community would help in planning communication strategies.

As communication channels quickly change and expand due to advances in technology such as Web sites and e-mail, evaluation of all current channels in a community, and how to best use those channels to reach different audiences, is recommended. Finally, additional research on the public's understanding after study results are announced would serve communicators in future investigations to further bridge the gap between the science and public perception of cancer clusters.

References

Aldrich, T. E. & Sinks, T. H. (2002). Things to know and do about cancer clusters. *Cancer Investigation*, 20(5&6), 810-816.

Asbury Park Press. Archived news articles on the Toms River cancer cluster study. Retrieved December 3, 2003, from http://www.tr-teach.org/ (Toxic Environment Affects Children's Health)

Breast Cancer Incidence and Mortality Trends in an Affluent Population: Marin County, California, 1990-1999. Northern California Cancer Center. Retrieved November 12, 2002, from http://www.nccc.org/ResearchandTraining/studies/pdf/bcr-4-6-clarke_marin.pdf.

Caldwell, G. G. (1990). Twenty-two years of cancer cluster investigations at the Centers for Disease Control and Prevention. *American Journal of Epidemiology*,132:S43-S47.

Cancer Clusters: Common Cause or Chance? (2002). Oregon State Cancer Registry. Retrieved November 11, 2002, from http:www.ohd.hr.state.or.us/oscar/.

Chess, C., Hance, B.J., & Sandman, P.M. (1988), *Improving dialogue with communities: A short guide to government risk communication.* New Jersey Department of Environmental Protection, as cited in ATSDR's *Primer on Health Risk Communication Principles and Practices*. Retrieved October 15, 2002, from http://www.atsdr.cdc.gov/HEC/primer.

Churchill County (Fallon) Childhood Leukemia Update. (2002, August 20). Nevada State Health Division. Retrieved November 13, 2002, from http://health2k.state.nv.us/HealthOfficer/Leukemia/fallon.htm

Covello, V. (1992). *Risk communication, trust, and credibility*, as cited in ATSDR's *Primer on Health Risk Communication Principles and Practices*. Retrieved October 15, 2002, from www.atsdr.cdc.gov/HEC/primer.

Covello, V. & Allen, F. (1988). *Seven cardinal rules of risk communication*, as cited in ATSDR's *Primer on Health Risk Communication Principles and Practices*. Retrieved October 15, 2002, from www.atsdr.cdc.gov/HEC/primer.

Cozzolino, L. (2002, April 24). *The Toms River Case – Testing and Trusting Science.* Abstract for University of Pennsylvania thesis. Retrieved March 25, 2003, from http://www.sas.upenn.edu/earth/eesmajor/ees_abstracts.html.

Dover Township Childhood Cancer Investigation Public Health Response Plan. (1996) New Jersey Department of Health and Senior Services. Retrieved November 16, 2002, from http://www.state.nj.us/health/eoh/hhazweb/dovertwp.htm

Draft Epidemiological Study of Dover Township Childhood Cancer Investigation Released for Public Comment. (2001, December 17). Retrieved November 10, 2002, from www.state.nj.us/health/news/p11218a.htm.

Fischhoff, B. (1999). Why (cancer) risk communication can be hard. *Journal of the National Cancer Institute Monographs*, 25, 7-12.

Fleming, D. (2001, June 5). *Identifying Cancer Clusters* -- Hearing Before the Senate Cancer Coalition. Retrieved November 12, 2002, from http://olpa.od.nih.gov/hearings/107/session1/reports/cancer_clusters.asp

Evaluation Primer on Health Risk Communication Programs, ATSDR (1997). Retrieved May 5, 2003, from http://www.atsdr.cdc.gov/HEC/evalprmr.

The Future of the Public's Health in the 21st Century. Institute of Medicine (2002). Retrieved November 22, 2002, from http://www.iom.edu/iom/iomhome.nsf/WFiles/AssuringFINAL/$file/AssuringFINAL.

Gawande, A. (1999, February 8). The cancer-cluster myth. *The New Yorker*, p. 34-37

Groves, M. (2003, February 22). Cancer cluster alleged. *Los Angeles Times.* Retrieved April 29, 2003, from http://www.latimes.com/news/local.

Healthy from the Start. Why America Needs a Better System to Track and Understand Birth Defects and the Environment. (2002). Trust for America's Health. Retrieved November 11, 2002, from http://www.healthyamericans.org/resources/files/healthystart.pdf,

Healthy People, 2010. (2002). Retrieved November 12, 2002, from http://plan2002cancer.gov/p-scpco.

Hoover, R. (2001, June 5). *Role of the NCI in Addressing Cancer Clusters* -- Hearing Before the Senate Cancer Coalition. Retrieved October 10, 2002, from http://olpa.od.nih.gov/hearings/107/session1/reports/cancer_clusters.asp.

Kolata, G. (2002, August 11). Ideas & trends: Proof; what causes cancer: Can science find the missing link? *New York Times*. Retrieved September 23, 2002 from http://query.nytimes.com/search

Kreuter, M.W. (1999). Dealing with competing and conflicting risks in cancer communication. *Journal of the National Cancer Institute Monographs*. 25, 27-32.

Las Vegan Sun, Articles on Fallon cancer cluster between July 2000 and February 2003. Retrieved February 13, 2003, from http://www.lasvegassun.com

Maibach, E. (1999). Improving cancer risk communication: a discussion of Fischhoff. *Journal of the National Cancer Institute Monographs*, 25, 14.

Marcus, A. C. (1999). New directions for risk communication research: a discussion with additional suggestions. *Journal of the National Cancer Institute Monographs*, 25, 35-41.

Moyers, Bill. (2002, May). Kids and Chemicals: A Special Report on the Scientific Search for Answers about How Environmental Toxins Affect America's Children. *NOW with Bill Moyers* on PBS.

New Jersey Cancer Cluster Tied to Water, Air. (2001, December 18). Retrieved October 18, 2002 from MSNBC News.

Newman, P. *Cancer Clusters Among Children: The Implications of McFarland*. Center of Community Action and Environmental Justice, Riverside California. Retrieved January 10, 2003 from http://www.ccaej.org/projects/canccluster.htm.

Public Health Assessment Guidance Manual Update. (2002). ATSDR Retrieved March 28, 2003 from http:www.atsdr.cdc.gov/HAC/PHAManual/appb.html#appb

Ratzan, S.C. (1999, February 15) Cancer risk communications: What we know and what we need to learn. *Vital Speeches of the Day, LXV, No. 9, 267-270.*

The Reno Gazette-Journal. Articles on Fallon cancer cluster between July 2000 and February 2003. Retrieved February 14, 2003 from http://www.rgj.com

Robinson, D. (2002). *Cancer clusters: Findings vs. feelings*. American Council on Science and Health, Retrieved November 12, 2002, from www.acsh.org/publications/booklets/clusters2002.html.

Rothman, A. J. & Kiviniemi, M. T. (1999). Treating people with information: an analysis and review of approaches to communicating health risk information. *Journal of the National Cancer Institute Monographs*, 25, 44-49.

Scientific Priorities for Cancer Research: Extraordinary Opportunities. Cancer Communications. (2002) National Cancer Institute. Retrieved October 24, 2002, from http://plan2002.cancer.gov.

Scott, G. (March 10, 1996). Kids' cancer rate alarms county – cluster of concern. *Star Ledger*, p. 1.

Sinks, T. E. (2001, April 12). *Fallon, Nevada.* Testimony Before the Senate Environment and Public Works Committee. Retrieved October 10, 2002, from http://www.cdc.gov/washington/testimony/ca041201.htm

Speaking of Health: Assessing Health Communication Strategies for Diverse Populations. (2002). The National Academy of Sciences. Retrieved January 10, 2003 from http://www.nap.edu/catalog/10018.html

Studying cancer clusters – a waste of time & money? (2001, April 9). Massachusetts Institute of Technology report in *Boston Globe.* Retrieved September 25, 2002, from http://www.cancerpage.com/cancernews/cancernews2625.htm.

Toms River cancer cluster settlement totals more than $13.2 million. (2002, January 25). Associated Press. Retrieved October 11, 2002, from http://www.enn.com/extras/.

Van Nevel, J. P. (1999). Introduction of section: Challenges inherent in communicating cancer risk information. *Journal of the National Cancer Institute Monographs*, 25, 5.

Walter, M. L., Kamrin, M. A., & Katz, D. J. (2000). *Risk Communication Basics.* Retrieved October 15, 2002, from http:www.facsnet.org/tools/ref_tutorial.

Ward, D. (1999, Spring/Summer). Cancer clusters: The complexities of mapping out clear cause and effect cancer relationships. *Frontiers*, 6 (3), 13-28.

Weinstein, N. D. (1999). What does it mean to understand a risk? Evaluating risk comprehension. *Journal of the National Cancer Institute Monographs*, 25, 15-20.

Wright, (2001, June 5). *Cancer Clusters* -- Hearing Before the Senate Cancer Coalition. Retrieved October 10, 2002, from http://olpa.od.nih.gov/hearings/107/session1/reports/cancer_clusters.asp

Appendices

Appendix A

Opinion survey on Childhood Cancer Cluster Investigation, Dover Township, NJ
State Health Department's Communication

1. I would characterize my initial reaction upon learning of the area's elevated cancer rates as upsetting.

1. Strongly agree__2. Somewhat agree __3. Neutral __4. Somewhat disagree __5. Strongly Disagree ___

2. I think the state health department communicated effectively about the situation initially after the news broke to the public in 1996 newspaper articles.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

3. I think establishment of the citizen liaison committee and the state health department's regular communications via this committee improved its communications and credibility.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

4. I think the agency communicated effectively by the end of the epidemiological study when the results were announced at January 13, 2003 public meeting.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

5. The study results stated that no environmental link was found for the children's brain and central nervous system cancers, but that pregnant women's exposure to contaminated well water and chemical plant air emissions appeared to have increased the risk for leukemia in their female children. I understand these results.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

6. I agree with the results based on the data and think the state did a credible study.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

Comments:

Interviewer's notes

Male ___ Female ___

Age Range 18-30 ___ 31-60 ___ Over 61 ___

Appendix B

Opinion Survey on Childhood Cancer Cluster Investigation, Fallon, NV
State Health Department's Communications

1. I would characterize my initial reaction upon learning of the area's elevated cancer rates as upsetting.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree ___

2. I think the state health department communicated effectively about the situation initially when elevated childhood leukemia rates were discovered.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

3. I think the state communicated effectively when state/CDC study results were announced at the Feb. 6, 2003 public meeting.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

4. I think the citizen support committee (CURT), working with the state, helped to improve communication and acceptance of the study and results.

1 Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

5. I feel that I understand the results of the study (after Feb. 6 announcements).

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

6. I agree with the results based on the data and think a credible study was done.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

7. I think the FIST citizen committee is conducting valid investigations and making an important contribution to overall knowledge of circumstances in Fallon/ChurchillCounty.

1. Strongly agree __2. Somewhat agree __ 3. Neutral __4. Somewhat disagree __5. Strongly Disagree___

Comments:

Male ___ Female ___

Age Range 18-30 ___ 31-60 ___ Over 61 ___

Appendix C

Questionnaire for interviews with state and federal health officials

1. What were some of the initial difficulties and misperceptions in communicating with community residents after news of the potential cancer cluster became public?

2. How would you characterize the public's initial reaction?

3. What are some of the lessons learned from your experience?

4. What recommendations would you give to others in similar situations for effective communication with the public?

5. How important is a citizen committee liaison in establishing trust and credibility with residents and victims' families?

6. How did you communicate with the press?

7. Do you think the public understood the limitations of the study and the results after they were announced?

8. Do you think there was effective communication during the study and at the end?

Appendix D

Response for communication recommendations from Martha Framsted, Public Information Officer for the Nevada Division of Health

Recommendations pertaining to cancer cluster investigation:

1) Implement a risk communication plan and follow the plan
2) Involve local media as partners:
    a) explain ground rules early in the investigation
    b) explain confidentiality limitations
    c) frequent/proactive communication with the media
    d) media briefings
3) When involving the national media, be aware of outcomes of media exposure (assess positive/negative ramifications, if possible, before involving national media)
4) Involve community liaison groups to:
    a) aid the families stricken with the disease
    b) educate the community regarding the disease and incorporate education pertaining to ongoing health concerns in the community
    c) involve mental health professionals
5) Include members of the community in the investigative process
    a) Include case family members on the advisory committee
6) Implement Town Hall Meetings to disseminate investigation results
7) Create a website that contains:
    a) disease information
    b) investigation information
    c) agency (local, state, federal) information
    d) contact information
8) Establish a Community Hotline (toll-free number)

Appendix E

Health Risk Communication Resources

ATSDR Public Health Assessment Guidance Manual Update resources:

ATSDR. n.d. *A primer on health risk communication principles and practices.* Agency for Toxic Substances and Disease Registry. http://www.atsdr.cdc.gov/HEC/primer.html. Provides a framework for the communication of health risk information to diverse audiences. Discusses issues and guiding principles for communicating health risk and provides specific suggestions for presenting information to the public and interacting effectively with the media.

ATSDR. 1997. *An evaluation primer on health risk communication programs and outcomes.* Agency for Toxic Substances and Disease Registry. http://www.atsdr.cdc.gov/HEC/evalprmr.html. Can be used to facilitate planning evaluations for risk communication programs. The primer informs decision-makers about what should be communicated, in what form, to whom, and with what expected outcome; identifies performance indicators; and provides guidance on how to use target audience ideas and opinions effectively to shape the risk communication message.

National Association of County and City Health Officials (NACCHO). *Don't hazard a guess: addressing community health concerns at hazardous waste sites.*
A practical hands-on guide. While the guide addresses hazardous waste sites, much of it is applicable to working with communities on landfill gas issues. Copies are available from NACCHO, Suite 500, 440 First Street NW, Washington, DC 20001-2030; telephone (202) 783-5550, or at www.naccho.org

Chess C, Hance BJ, Sandman, P. M. 1991. *Improving dialogue with communities: a risk communication manual for government.*
Summarizes practical lessons for communicating about environmental issues. Available from the Center for Environmental Communication (CEC) http://aesop.rutgers.edu/~cec/ at Rutgers University.

National Research Council. 1989. *Improving risk communication.* Washington, DC: National Academy Press; 1989.
Provides guidance about the process of risk communication, the content of risk messages, and ways to improve risk communication.

EPA. 1991. *Air pollution and the public: a risk communication guide for state and local agencies.* Air Risk Information Support Center. Research Triangle Park, North Carolina. EPA 450/3-90-025.
Examples of effective methods in presenting public health risk information to the public.

Williams, R.C., M. Lichtveld, S. O. Williams-Fleetwood, and J. A. Lybarger. 2000. *Communities at the center: in response to community concerns at hazardous waste sites.* Envtl. Epi. and Toxicol. (2000)2:56-66.
Highlights ATSDR's philosophy pertaining to effective community involvement.

Online Resources

American Industrial Hygiene Association (AIHA)
Founded in 1939, AIHA is an organization of more than 13,000 professional members dedicated to the anticipation, recognition, evaluation, and control of environmental factors arising in or from the workplace that may result in injury, illness, impairment, or affect the well-being of workers and members of the community. As part of a continuing education program, AIHA offers an Effective Risk Communication Training Series.
http://www.aiha.org/

California State University at Northridge (CSUN)
The Risk Communication Forum provides links to key sources of environmental health risk information and to fellow professionals in the environmental health community.
http://www.csun.edu/~vchsc006/tom.html#Introduction

The Center for Environmental Communication (CEC)
The CEC at Rutgers University brings together university investigators to provide a social science perspective on environmental problem-solving. CEC (formerly the Environmental Communication Research Program) has gained international recognition for responding to environmental communication dilemmas with research, training, and public service. http://aesop.rutgers.edu/~cec/

The Center for Environmental Information (CEI)
CEI is a private, nonprofit educational organization founded in Rochester, New York, in 1974. CEI's Environmental Risk Communication Program offers training, resources and skills to enable all parties involved in an environmentally risky situation to work together toward a mutually acceptable outcome.
http://www.rochesterenvironment.org/

The Risk Communication Network
The Risk Communication Network is a project initiated by the World Health Organization Europe (WHO Europe) and coordinated by the Centre for Environmental and Risk Management (CERM). The risk communication network staff produces RISKOM, a regular newsletter outlining developments in risk communication throughout Europe and beyond. Network membership and the newsletter are free.
http://www.uea.ac.uk/env/cer/

University of Cincinnati Center for Environmental Communication Studies
The mission of the Center is to enhance the understanding and quality of communication processes and practices among citizen, industry, and government participants who form and use environmental and health policies. http://www.uc.edu/cecs/cecs.html

The University of Tennessee College of Communications offers seminars on risk communication. http://excellent.com.utk.edu/. Crisis communication links and environmental issues links can be found at http://excellent.com.utk.edu/~mmmiller/riskcom.html

Other resources

CDC's cancer clusters web site at http://www.cdc.gov/nceh/clusers/default.htm

CDCynergy, *Your Guide to Effective Health Communication.* (2001). Centers for Disease Control and Prevention, Office of Communication. Available through http://www.cdc.gov/communication/.

Health Communication Division of the National Communication Association web site contains a list of institutions potentially offering programs or courses in health communication at: http://www.sla.purdue.edu/healthcomm/

Making Health Communication Programs Work. (2002). Department of Health & Human Services, National Institute of Health. Available through www.cancer.gov.

NCI's cancer cluster web site at http://cis.nci.nih.gov/fact/3_58.htm.

Risk Communication Hotline.
Responds to questions on risk communications issues and literature, provides information on EPA's Risk Communication Program, and makes referrals to other related agency sources of information. 202-260-5606, Monday through Friday, 8:30 a.m. to 5 p.m.