Cancer cluster investigations need to address the disconnect between traditional public health approaches and human needs. Cancer cluster investigations often magnify fear and uncertainty because they rarely find a definitive environmental cause. Traditional approaches emphasize population-level data analysis and undervalue active listening. Because few studies have explored active listening in cancer cluster investigations, we conducted a descriptive oral history case study of a Frederick, Maryland, investigation. We interviewed 12 community members and 9 public health professionals about the investigation of a perceived cancer cluster. Many believed it was linked to environmental contamination at Fort Detrick, a local US Army base. We propose enhanced active listening that seeks out peoples’ perspectives, validates their concerns, and engages them in the investigative process. (Am J Public Health. 2014;104:1204–1208. doi:10.2105/AJPH.2013.301836)

A cancer cluster is “an excess number of observed cancer cases or deaths by place and time.” Every year in the United States, more than 1000 reports of suspected cancer clusters are made to public health authorities. An estimated 70% to 95% of these reports are resolved through a phone conversation with the informant or a letter from the state. Most reports do not require investigation because they can be explained through education, for example, by describing how common cancers are (people have “a one in three lifetime probability” of receiving a cancer diagnosis) and how risk for cancer increases with age.

For the reports that do warrant a follow-up investigation, typically cancer incidence in the population of interest is compared with statewide cancer rates. In a small percentage of these investigations, the number of cancer cases exceeds the expected number for the population of interest within a specified period of time. Chance, however, can explain a significant number of these suspected clusters.

Of the relatively small number of cluster investigations conducted, very few, if any, are able to establish a clear environmental cause. A review of 428 suspected cancer cluster investigations in the United States evaluating 567 cancers of concern from 1990 to 2011 found that only 1 was linked to a clear cause—and that was occupation related. Asbestos-exposed shipyard workers in South Carolina experienced an increased rate of pleural cancers. Goodman et al. concluded, “It is fair to state that extensive efforts to find causes of community cancer clusters have not been successful.”

A prior review of 108 cancer cluster investigations by the Centers for Disease Control and Prevention (CDC) from 1961 to 1982 found that no clear cause was determined in any of the clusters.

For these reasons—and because of finite resources—public health officials must consider other needs before embarking on cancer cluster investigations that will be difficult and unlikely to produce definitive results. Indeed as a 1990 editorial in The Lancet noted, “The cluster alarm can become the epidemiologist’s nightmare.”

However, people who have lost loved ones to what they believe is a cancer cluster have a very different definition of “nightmare.” They want to know what caused the suspected cluster, who is at fault, and how they can protect themselves and their loved ones in the future. Confronted with unexplained and unseen threats, community members often believe immediate attention and action are needed. As Trumbo et al. noted, because many factors can create the appearance of a cluster when the existence of a cluster cannot be confirmed, health officials who respond to cluster inquiries must face the extra challenge of addressing public concerns about a topic fraught with scientific uncertainty and a great deal of fear.

In its original 1990 guidelines on cluster investigations, the CDC noted, “From a public health perspective, the perception of a cluster in a community may be as important as, or more important than, an actual cluster.” Local media coverage can feed perceptions that a cluster exists, increasing fear about cancer risks and concerns about other impacts such as reduced property values.

When investigative results are not immediate or to their liking, residents can feel frustrated and angry. To them, proving a cluster exists and finding its cause are worth any expense. As 1 cancer survivor told us, “They say there’s not time or money to do a proper job. Believe me there’s not time or money to have cancer” (cancer survivor, oral communication, July 2012).

CONFLICTING APPROACHES

Community members’ desires to find an environmental cause for cancer in their community are in direct conflict with an investigation’s often inconclusive findings. Their perception of a significant threat and the human impulse to seek an immediate response also conflict with the time needed for careful data analysis. Two-way communication can reduce tensions and inform the public about cancer epidemiology. However, communication in cancer cluster investigations has not traditionally been emphasized; when it was discussed, it typically focused on 1-way communication.
promise, there is much work to be done, as
that positive changes are forthcoming.13
by enhancing rather than minimizing commu-
opportunity to engage more fully with the public
cancer cluster investigation. There is a great
human needs of a population in a suspected

Fort Detrick, a still-active base with more
than 4000 employees, was the national center
for offensive biological weapons research from
1943 to 1969.15,16 Fort Detrick’s Area B is a
399-acre parcel that was formerly used as a
testing area for biological weapons and as a
disposal site for “biological materials, test ani-
mal carcasses, radiological tracer materials,
phosgene cylinders, and drums containing
organic solvents.”17,18 Buried drums of
tetrachloroethylene, trichloroethylene, and
other organic solvents led to groundwater
contamination.18 The herbicide known as
Agent Orange was also tested in garden plots
there.19

On April 9, 2009, at the Maryland Depart-
ment of Environment’s request, the US Envi-
ronmental Protection Agency added Area B to
the Superfund’s National Priorities List.20 In
response to community concerns, the Maryland
Department of Health and Mental Hygiene
(DHMH) and the Frederick County Health
Department (FCHD) initiated a cancer cluster
investigation in June 2010. The investigation
examined cancer rates within 1- and 2-mile
radii of Fort Detrick and included a review of
Maryland Cancer Registry data collected since
1992 (the year of the registry’s inception) and
US Census data.21 That summer, public meet-
ings led by a community group known as the
Kristen Renee Foundation drew large crowds
and attracted significant community interest
(Randy White launched the foundation after
his 30-year-old daughter, Kristen Renee, died
of brain cancer.22) On August 12, 2010, Barbara
Brookmyer, the Frederick County health office,
convened a public meeting for the community
to voice their concerns and ask questions. More
than 200 people attended the meeting.

On October 3, 2011, DHMH and FCHD
released a summary report of their investiga-
tion. It did not find evidence of a cancer cluster
although lymphoma rates were slightly higher
in the study area than was the rate in Maryland
(but not higher than the rate in Frederick
County).21 The state and local health depart-
ments pledged to reexamine lymphoma rates
as future Maryland Cancer Registry data be-
come available.21

At the Army’s request, a National Research
Council committee evaluated the DHMH and
FCHD cancer investigation and a 2009 in-
vestigation by the Agency for Toxic Substances
and Disease Registry that found contaminated
water wells were unlikely to have produced
harmful effects, including cancer.23 In its Feb-
ruary 2012 report, the committee found that
the lack of groundwater measurements before
1992 made it impossible to reconstruct past
exposures and determine any health effects
that likely would have resulted.23 It also found
that the DHMH and FCHD conclusions were
valid but noted, “Because of the limitations
inherent in cancer cluster investigations, no
study will be able to provide definitive find-
ings.”23 The committee advised against
conducting additional studies.17

COMMUNITY CONCERNS ABOUT
THE INVESTIGATION

Frederick residents and others had
expressed concerns about the health effects of
the Fort Detrick facility for decades.23 Fort
Detrick’s 1993 official history noted, “Files are
jammed with news clippings from front page
articles charging Fort Detrick as the culprit in
a community environmental problem.”23
However, it also stated that “to date” no
laboratory accident at the base had ever af-
fected the community, although it lists the
deaths of a microbiologist in 1951, an electri-
cian in 1958, and an animal caretaker (un-
dated) from anthrax, pulmonary anthrax, and
Machupo virus, respectively.23

The residents we interviewed felt the Army
had long ignored them. One person told us
that even in recent years the residents could
not get “straight answers”:

The people at Fort Detrick . . . [will say], “we’ll
check into it and get back to you next month at
our meeting.” But then you don’t hear anything,
or they’ll say the records are lost or that in-
formation has to come from somebody higher
up, but you never hear. And so we just feel
they’re just blowing us off. (Frederick resident,
oral communication, July 2012)

Most of the community was not satisfied
with the DHMH and FCHD investigation. Their
reactions are categorized in Table 1.

IMPlications FOR pUblic HEALTH
OFFICIALS

To bridge this chasm between the public and
public health officials, we believe that at every
step health officials need to recognize the fear,
uncertainty, and suffering caused by suspected
cancer risk, regardless of its actual origins or
biological plausibility. Acknowledging the
human dimensions implicit in cancer cluster
investigations can encourage public health
professionals to embrace 2-way communica-
tion with community members and value them
as important resources for the investigation.

Many public health professionals have seri-
ous concerns about the value of cancer cluster
investigations. In the past, some states even had
burdensome requirements essentially designed
to dissuade reports of suspected cancer
clusters.2 Clearly, a more responsive process is
warranted—despite health departments’ limited
resources. Bender et al. demonstrated how the
Minnesota Department of Health could be
“responsibility responsive” in addressing clus-
ter concerns and easily resolve 95% of in-
formants’ reports by empathetically informing
respondents or examining readily available
The 4 steps of the 2013 CDC guidelines offer a rational method for achieving this without unnecessarily committing resources to a major investigation.

In our view, evaluations should begin with understanding and acknowledging how the public may view and emotionally respond to a suspected cancer cluster. Experts and laypeople have been shown to come to very different conclusions about risk when presented with the same information. Levy et al. demonstrated that laypeople have difficulty accepting randomness and naturally seek patterns to link causes to events. For example, the proximity of industrial sites or landfills (in the case of Fort Detrick) can “galvanize” risk perceptions and make it difficult for people to accept that a cluster is the result of random chance. When Levy et al. presented people with facts about a hypothetical scenario of cancers on 1 neighborhood block, the laypeople were even alarmed by facts that were meant to be neutral or reassuring. Levy et al. report,

These vastly different interpretations of the same data no doubt contribute to the unsuccessful and problematic communications that often ensue between public health officials and community members when concern about a cancer cluster arises.

Clearly, as they communicate with people, health officials need to be aware of different perceptions the public may have about suspected cancer clusters.

A NEW APPROACH TO LISTENING TO THE PEOPLE

Another critical part of cancer cluster communication for public health officials is listening to community members. Several of the public health professionals we interviewed emphasized its importance. Barbara Brookmyer, the Frederick County health official, reflected on her department’s involvement this way:

If we did something well, my perspective is that it might be the listening part. There was a long history of folks from the community feeling as though they hadn’t been listened to, and even if they were listened to, there was no documentation that any discussion(s) ever took place. Listening is really the first step to being able to improve the awareness and the communications. It was a very good first step to just listen. And it wasn’t easy. We spent more than 5 hours over 2 meetings just listening. (Brookmyer, MD, MPH, oral communication, August 2012)

Listening not only makes public health officials more credible with the community members, it can yield unexpected insights (Cliff Mitchell, MD, MPH, MS, oral communication, September 2012). Mitchell, director of

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**TABLE 1—Community Member Responses to a Cancer Cluster Investigation: Frederick, Maryland, 2012**

<table>
<thead>
<tr>
<th>Category</th>
<th>Comment</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suspicion</td>
<td>“I think it’s been a sham. . . . The state has totally incomplete data, but they tried to give the image that they had their act together and that ‘No we can’t prove or disprove there is a cluster.’”</td>
<td>Engineer and Frederick resident (oral communication, July 2012)</td>
</tr>
<tr>
<td>Accusation of incompetence</td>
<td>“I have never seen so much bullshit in all my life. It is the saddest thing I’ve ever witnessed. You’ve got the state of Maryland trying to pull together evidence that there is no cancer cluster. Number 1, they’ve admitted many, many times they don’t have the finances. Second, what they’re doing [in the investigation] is so antiquated and archaic. It’s like cavemen writing on walls. They are not up to the 21st century with technology.”</td>
<td>Community organizer and family member of cancer victim (oral communication, July 2012)</td>
</tr>
<tr>
<td>Anger</td>
<td>“[The state says] that it didn’t have nothing to do with Fort Detrick; ‘Just because all your family died from cancer, it didn’t have nothing to do with Fort Detrick. That’s not a cancer cluster.’ Well dammit, my family alone is a cluster.”</td>
<td>Frederick resident who lost 13 immediate family members to the same rare cancer (oral communication, July 2012)</td>
</tr>
<tr>
<td>Inadequate data</td>
<td>“A lot of my concerns were people that were exposed and were around the stuff in the 50s and 60s. And a lot of those people died in the 70s and 80s and none of that data is available in the investigation [in the cancer registry]. So you know, we can say from 1992 to 2000, X number of people developed cancer. But there’s an awful lot of people that there’s no one to speak for now, that died before [1992]. That kind of invalidates their findings.”</td>
<td>Business manager and Frederick resident (oral communication, July 2012)</td>
</tr>
<tr>
<td>Survivor’s viewpoint</td>
<td>“I have tumors in my thyroid. I have a mass on my pancreas, which gets biopsied every 6 months, and I have no breasts. And I believe that this was all caused by environmental exposure that nobody will ever do any critical thinking long enough to look into.”</td>
<td>Cancer survivor (oral communication, July 2012)</td>
</tr>
<tr>
<td>Personal experience</td>
<td>“My dad died of pancreatic cancer. My sister died of brain cancer. My wife died of ovarian cancer. My dog died; he was ate up with cancer. My cows had cancer. So they can’t tell me that they didn’t do something.”</td>
<td>Farmer who lived next to Area B (oral communication, August 2012)</td>
</tr>
<tr>
<td>Concern for the future</td>
<td>“I just hope the day doesn’t come when something down there gets out and we all regret that something wasn’t done before. I firmly believe that’s a possibility, and I don’t want to see that happen.” [Context: Several community members expressed concern about averting future cancer cases, especially in new housing developments planned for land adjacent to Area B.]</td>
<td>Business manager and Frederick resident (oral communication, July 2012)</td>
</tr>
</tbody>
</table>

Note. These reactions, evident in the tense public meetings and the postinvestigation bitterness, reflect the chasm separating the public and public health officials. This division was perhaps best exemplified when a resident declared to a health official at a public meeting, “I have no confidence in your confidence intervals.”
DHMH’s Environmental Health Bureau, described his process to us. First, he informs the public of how he approaches a cancer cluster investigation, evaluating exposure possibilities, community demographics, occupation details, and other facts that might point to the biological plausibility of an exposure that could be linked to a cancer (Mitchell, 2012). Then he asks people about their background and perceptions:

In asking the questions where do people work, what kind of work do they do, what are their hobbies, their habits, oftentimes in listening to their answers you might find something unexpected. For example you might find that people consume a lot of native fish and they are fishing in an area where there are fish that potentially have high levels of something in it. You wouldn’t know that unless you sort of walk through that process. So for me, it’s a very iterative process. (Mitchell, 2012)

Information gleaned by listening to community members should be taken seriously. (Thomas Burke, PhD, MPH, oral communication, September 2012) Burke, a veteran cancer cluster investigator who worked for 13 years with the New Jersey departments of Environmental Protection and Health, told us,

The most important thing is to have a dialogue and listen because communities don’t make this up. There are reasons they are concerned, and usually they’re right about some degree of risk. And usually a town can make progress by addressing those risks. (Burke, 2012)

EDUCATING THE PUBLIC

Interactions with the concerned public also provide opportunities to educate people about clusters as well as causes of cancer. Promoting education and screening to people concerned about a cancer cluster may not yield answers about the cluster, but these actions "inform people, encourage a sense of self-control and improve cancer outcomes." (Mitchell, 2012)

In educating the public about cancer and the investigative process, John Bailar, who led the National Research Council committee review of the Frederick investigations, recalled some sage advice he once heard:

Never overestimate the knowledge of—people in the public nor underestimate their intelligence. You have to treat them as intelligent, concerned beings who are capable of learning what they need to know and deal with them on really an adult basis. There’s no excuse for dumbing down. (Bailar, MD, PhD, oral communication, October 2012)

Although the community members we interviewed were not satisfied with the investigations’ findings, they did appreciate FCHD’s efforts on their behalf. These engagement efforts may prove instructive for public health officials who seek to defuse tense situations and enhance their cancer cluster investigations. At the initial public meetings, the FCHD staff wrote down every question that the public had and solicited answers from the various agencies involved. The questions and answers were compiled and posted online. In addition to being able to get specific answers to their questions, the public felt they were taken seriously (Brookmyer, 2012). Thun and Sinks describe such efforts as providing "a structured process within which individuals can voice their concerns and support informed community decision making." (Thun & Sinks, 1990)

Brookmyer formed a Technical Advisory Committee (TAC) of interested residents in October 2010 to meet regularly to provide input into the process and consider alternative means of investigating the cancer issue. This brought the most committed members of the community into the process not only to voice complaints but also to look for solutions. In fact, TAC members had the idea of documenting their experiences through oral histories, and Brookmyer approached us with the request to take on this project. The TAC also has yielded creative ideas for new investigations. Two case–control studies proposed by TAC members are being launched: 1 seeks to compare cancer rates in the community surrounding Fort Detrick with 2 “control” communities more distant from the base; and another will attempt to compare cancer rates of former students of an elementary school next to Fort Detrick with those of another school in the area. (Brookmyer, 2012). As Brookmyer told us,

I look at it as a large puzzle that we will never be able to fill in all the pieces to see the whole picture, but there might be different approaches that we can start to fill in some of the pieces. (Brookmyer, 2012)

COLLECTING ORAL HISTORIES

The collection of oral histories provides another means of engaging people and validating community concerns. By stopping and listening to the people and collecting their oral histories on video, we found the interviewees to be grateful for the opportunity to share their perspectives and to be heard. One resident told us,

The best thing that’s happened to me is when you called me. My daughter took the message—she has cancer. I told [her] I can’t believe anybody independent like you all [at Johns Hopkins] would even try to help us or do anything. I’m very thrilled to have you all try to do something for us. (farmer and Frederick resident, 2012)

When we reported back to the TAC about our findings and played video excerpts from our interviews, TAC members were clearly grateful and proud of their contributions—even though this project did not evaluate the cluster investigation or comment on its findings. Such responses to our project indicate the practice community should consider suggesting the collection of residents’ stories.

The health department itself does not have to conduct the oral history interviews or incur their expense. In fact, our student project did not require any FCHD resources. The size and scope of the oral history project can vary depending on the community’s desires as well as resources and partnerships available. We suggest that the agency responsible for the investigation not collect the oral histories to avoid the appearance of controlling the community’s narrative or censoring certain comments. Enlisting a third party allows the health department to conserve financial resources while also empowering people to control their own narrative. Possible third parties to conduct an oral history project may include a wide range of organizations and individuals, such as students in public health, journalism, communications, or other programs at local universities and community colleges. Retirees and other volunteers with related experience may also be willing to help. Alternatively, the concerned community members themselves can conduct the interviews. Regardless of who completes the oral histories, they can be a valuable compilation of the community’s concerns and experience.

Furthermore, collecting personal stories may elicit anecdotal information that can inform the research questions. Even if the stories do not add any explicit scientific benefit, they can still enhance the understanding of the human
impact of suspected cancer clusters. And perhaps more importantly, listening to residents’ stories can demonstrate investigators’ concern and provide comfort and validation to cancer-affected community members.

CONCLUSIONS

Responding to community members concerned about a suspected cancer cluster is a critical public health responsibility. Responses should go beyond data analysis and recognize the human needs of the community. Bailar advised that public health officials need to understand all they can about the concerns of the public and then to treat those concerns seriously—whether [they] think they’re justified or not. If the public is concerned, that’s an important matter. (Bailar, 2012)

Seen from this perspective, cancer cluster investigations provide opportunities to engage with the community on multiple fronts, including to help people concerned about cancer or other potential health effects; engage people in important public health conversations by listening as well as sharing information; involve people in the investigation process and utilize them as important resources; and inform them not only about clusters but also about the causes of cancers and their prevention.

The CDC’s 2013 guidelines offer great promise in this direction by advising practitioners to make the most of the opportunities we have discussed. On the basis of our qualitative findings in Frederick, we view an emphasis on communication as a much needed advance in conducting cancer cluster investigations. We also believe that oral histories serve as a valuable addition to the process; community storytelling empowers concerned residents and allows them to feel their perspectives and experiences are valued. We encourage public health officials to adopt these enhanced communication approaches that acknowledge the public’s concerns, fears, and responses to suspected cancer clusters. Understanding the public’s perspectives by listening to them will help public health officials bridge the chasm that separates investigators from the concerned community members.

Video excerpts of the Frederick, Maryland oral history interviews and advice for communities and public health professionals can be found on the Web site Cancer Cluster Investigations: A Case Study and Resources.

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Contributors

B. W. Simpson and P. Traunt conducted key informant interviews and performed document research. B. A. Resnick supervised the study. All authors participated in the analysis and contributed to writing the article.

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