Public Requests for Cancer Cluster Investigations: A Survey of State Health Departments

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A B S T R A C T

Objectives. This study examined the frequency of requests that state health departments investigate cancer clusters, the nature of those requests, and the resources available for the investigations.

Methods. A mail survey was sent to state health departments requesting data for 1997.

Results. Approximately 1100 cluster investigation requests were made in 1997. Most requests were made by citizens, and no pattern emerged for types of cancer or hazards suspected. States rate this work as average in importance and feel satisfied with the successfulness of their communication efforts.

Conclusions. Few cluster inquiries require further investigation. Nonetheless, this interaction represents resources well spent in terms of public service and education. (*Am J Public Health.* 2000; 90:1300–1302)

State health departments often serve as the resource of first choice for a citizenry ever more concerned about the incidence of cancer. Citizen alarm specifically over cancer clusters has reached such a level that, according to a story in the *New York Times*,[1] this "public clamor" is influencing the nature of basic research being conducted on cancer. Other articles have appeared recently in the national press describing "the cancer cluster myth."[2] A casual search of any general news database (e.g., Lexis/Nexis) reveals that the term *cancer cluster* has become part of the popular lexicon.[3–5]

What is the nature of this phenomenon? In 1989, state health departments in the United States received a total of 1300 to 1650 requests to investigate suspected cancer clusters.[6] Examinations of how these investigations were done have included a review of work done at the Centers for Disease Control and Prevention (CDC)[7] and evaluations of state epidemiologic and communication protocols.[6,8–10] The raw increase in cancer in an aging population and the phenomenon of the "random cluster" are certainly associated with the frequency of citizen complaints over cancer rates.[11,12] Other factors, such as increased environmental awareness,[13,14] disclosures of hazardous waste sites,[15] and media attention to cancer, are probably implicated as well.[6]

This report, which is part of a larger study of the social psychology of cancer clusters,[16–21] updates previous studies examining the frequency of requests for cluster investigations and the nature of state responses. It also provides information on 3 unexamined aspects of cluster investigations: the complainants, the cancers of concern, and the perceived hazards. Additionally, it evaluates the occurrence of citizen involvement in these investigations—what has been termed "popular epidemiology."[14,22–26]

Methods

Health departments were surveyed by mail, according to standard procedures, in early 1998.[27] Instructions emphasized that the survey was about cancer clusters, not disease clusters generally. Only Ohio refused to participate. In addition to asking general questions, the survey asked for specific details about all cluster investigation requests made in 1997. States were required to access records to provide this information; 29 states were able to comply. In total, 428 cluster cases were detailed (40% of the total). Although these data are incomplete, they can at least provide some insight into the experiences of many state health departments.

Results

Results involving the number of complaints and the characteristics of state health department reactions are presented in Table 1 (a supplementary table with a state-by-state breakdown is available from the author). A few additional notes on these results are made here, as well as a report of the detailed examination of the 428 cases.

Number of Complaints

Five states were not able to provide information on the number of complaints made. If these missing data are estimated by median substitution (eliminating California's undue influence), a fair estimate for the national total is approximately 1100 (close to the 1989 figure). Concerning the perceived increase, a few respondents wrote comments indicating that while the number of complaints was not up dramatically, the intensity of community concern in these cases has increased.

State Responses

Regarding the nature of state responses, in addition to the averages reported in Table 1, correlations were made among the last 7 variables listed in the table. Two are worth noting. Previous research showed a positive correlation between states' having resources available for cluster investigations and the number of investigations made.[10] This still holds true, with a correlation of 0.42 ($P<.05$) between the number of requests made in 1997 and the level of personnel resources available. The number of requests made in 1997 is also correlated with

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TABLE 1—Number of Public Requests for Cancer Cluster Investigations and Characteristics of State Health Department Reactions to Requests

States conducting cluster investigations, %	93
States with standing response protocol, %	67
States regularly issuing reports on cancer rates, %	67
States that have ever formally evaluated communication of cluster information	2 (Missouri and Wisconsin)
No. of Persons available for cluster investigations (on average)	<0.25 (57%) 0.5–1 (32%) >1 (10%)
Importance of cluster investigations relative to other tasks (1 = unimportant, 7 = important)	Average (mean = 3.5)
Perceived satisfaction of complaints (1 = satisfied, 7 = unsatisfied)	Average (mean = 3.5)
Complaints satisfied at first contact (via phone), %	75 (mean = 65, median = 75)
Total investigation requests from the public in 1997	1024 (mean = 22, state median = 9)
Perceived increase/decrease of complaints (1 = decrease, 7 = increasing).	Perception of slight increase (mean = 4.6)
Complaints associated with legal action, %	<5

the ranking of the importance of this work (0.30 [$P = .05$]).

Popular Epidemiology

Overall, the results do not indicate that popular epidemiology is widespread. States reported that most investigation requests (83%) were motivated by general or informal feelings about cancer rates, and that the requesting party presented data, expert consultation, statistical analysis, or mapping in only about 3% of cases. Also, states did not report that many of their investigation requests were associated with cases involving legal action, with half of the respondents indicating they saw no such cases in 1997. However, 10 states did indicate that at least 10% of that year's investigations were linked to lawsuits.

Sources of Investigation Requests

In 65% of the 428 cases on which detailed information was provided, investigation requests came directly from citizens. About 10% of the cases involved a local health agency, with the balance distributed among the other categories (physicians, news media, federal or state agencies, elected officials, others). Although often very involved in covering cluster investigations, the news media were direct participants in the initiation of cluster investigations in only 3% of the cases reported.

Cancers of Concern

Again drawing on the 428 detailed cases, results show that the average number of cancer locations specified in investigation requests was just under 2—ranging from only 1 site (specified by 65%) to 5 or more (specified by 6%). In terms of the specific cancers of concern, 30% of requests were based on nonspecific cancer concerns ("various cancers"). Leading the list of specific cancer concerns were breast cancer (26%), leukemia (18%), brain cancer (17%), and lung cancer (15%). Cancers of the male and female reproductive organs, colon cancer, and pancreatic cancer each showed up in 5% to 9% of the investigation requests.

Perceived Hazards

A categorization scheme was developed for the range of perceived hazards. The coding scheme included the following: none specified, multiple hazards, radiation (from uranium mining, power plants, research facilities), agricultural chemicals (herbicides, nitrates, pesticides, DDT, chemicals from golf course and lawn care spraying), industry (contaminants from Superfund sites, landfills, mining, and dumps; dioxin; chlorine; polychlorinated biphenyls [PCBs] and other emissions if not specified as water or indoor air pollution), travel (auto emissions, benzene, methyl tertiary butyl ether [MTBE], emissions from airports and road construction), indoor air (including radon and asbestos), and contaminated water.

The largest single category was "none specified," with 40% of requests not specifying a possible causal mechanism. A direct concern over some industrial situation accounted for 21% of the requests; water and multiple causes for about 8% each; other, indoor air, and agricultural pollution for about 7% each; radiation for 3%; and travel for 2%.

Discussion

Despite perceptions to the contrary, the rate of requests for cluster investigations in 1997 had not changed appreciably compared with 1989. It is possible that 1989 was an unusual year, followed by a reduction and a subsequent increase in requests. In any case, the number of such requests should be tracked.

With respect to the public's perception, these results paint a picture of citizens holding a fairly generalized concern about cancer rates, usually without specifically identified cancers or hazards (although some notable exceptions can be found). Although the data reported here show no relationship between the public's perception of specific cancers and its perception of potential causes, the possibility that such a relationship exists has been ignored in research and should be reexamined. Further, although popular depictions of salient cases (such as in Woburn, Mass, where citizens conducted their own investigation of industrial contamination of drinking water[28]) could lead one to think otherwise, activity that could be termed "popular epidemiology" is fairly uncommon. In most cases, citizens and others who approach their health departments for answers about cancer rates do not marshal their own evidence or analysis. And although legal action associated with cluster investigations is uncommon, it may be on the increase in some states. This bears watching.

Of the more than 1000 complaints about cancer rates that are received by state health departments every year, very few are determined to require significant investigation. Because of the imperfection of epidemiologic tools and data, the nature of the disease, and other factors, clusters are rarely identified. Still, the interaction that state health departments have with communities over suspected clusters represents resources well spent in terms of public service and education. Further, these cases have contributed to the establishment of state cancer registries and have helped make these archives active participants in cancer surveillance and control. □

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