Commentary

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Epidemiology for and with a Distrustful Community

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The epidemiology of diseases associated with chemical waste disposal sites has often been delayed for years after the affected community became aware of the exposure. Frequently, this has resulted in an aroused neighborhood community that is distrustful of those public agencies and officials responsible for protecting their health. It is thus important that positive steps be taken to alleviate the antagonism and to involve the community in an active and constructive role in the epidemiology study. This paper presents a case history of such an incident and highlights some of the lessons learned.

The first steps were to involve and inform the community. A citizen and industry advisory committee was formed to participate in the work, publish a newsletter, and conduct regular community meetings. The newsletter and the community meetings were used to identify problems and to explain them; to describe uncertainties of a scientific as well as of political or financial nature; to involve community leaders, including those distrustful; to conduct an epidemiologic census and a neighborhood environmental exposure survey.

The end results were a defusing of the antagonism toward authorities, complete acceptance by the community of the merit of the report, a higher quality of report than might otherwise have been possible, and the freedom to move toward alleviating the problems of the disposal site.

Introduction

Hazardous waste dumpsite epidemiology has up to the present been primarily initiated by prolonged demands for investigation by the affected communities. By the time the epidemiologist arrives on the scene, years may have gone by, and the various factions in the community are often at odds with each other and distrustful of any outside official whom they fear may continue to play down or even cover up any health effects of the site.

These dumpsite studies are not sensitive instruments for detecting the relatively small increments of disease incidence which are of regulatory interest because of small sample sizes, uncertainty about exposure, short followup periods, and the lack of definitive laboratory tests to indicate exposure or preclinical insult. Demonstrated increases in the more common subjective complaints, which often occur around these sites, can be attributed to a variety of methodological biases.

For these reasons the client communities, though asking for a definitive resolution of their health questions, are often left with only a modest reduction in the range of uncertainty and potential for controversy and differing interpretation of results. This means that early and continuing involvement of various community factions is essential to make sure that the community has enough input into the process of the study and the interpretations of results to assure themselves that a good faith effort has been made.

Our title also talks about epidemiology with a distrustful community. Residents near a hazardous waste site, like workers in a plant, have a number of potentially valuable epidemiological roles to play. They are often the ones who first notice an unusual occurrence of disease. They have the best insight into the potential ongoing routes of exposure. They may be aware of transitory episodes of high level exposure (e.g., a particular neighborhood flood). They have a legitimate role in pointing out the implications of alternate interpretation of the results and making sure that matters of scientific judgment are not disguised as matters of scientific fact.

Finally, community members can be helpful in the design, conduct, and interpretation of an epidemiological study as long as their role does not violate the confidentiality of their neighbors or lead to possible biases (or the appearance of possible biases) in the study. In a recent Los Angeles study, community members suggested topics (but not exact questionnaire items) to be covered in a study and carried out a door-to-door census (results were sealed in an envelope and carried back unopened to the Health Department to maintain confidentiality). Thus, working with an affected community, when correctly done, can improve the scientific quality of a study. It can also foster better understanding and acceptance of the final results. This kind of involvement of study subjects is quite contrary to usual epidemiological practice, which tries to keep the sub-

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jects as unaware as possible of the hypothesis being tested. However, dumpsite epidemiology has a different audience than traditional epidemiology.

In a traditional epidemiological situation, the decision to do a study is that of the epidemiologist. The epidemiologist writes for other scientists who may regard him or her with some muted scientific skepticism, but who look carefully at the materials and methods section and decide on the basis of that whether or not to believe what he or she says. They share basically the same beliefs about physiology and toxicology and have the same kind of sophistication about statistics. In dumpsite epidemiology, however, the decision to do a study is often made by the affected community. The audience, although many epidemiologists do not realize this, is really the affected community, and only incidentally other scientists. The attitude towards the study may be outright distrust. There is distrust about one's motives and qualifications: Are you covering up? Are you in league with industry? If you are in a state health department, are you competent?

The people in the community do not share our views on what is physiologically possible and not possible. They certainly feel uncomfortable with probabilities and view talk about "lifetime risks" as if someone were gambling with their health. In many ways, this is like dealing with a distrustful patient from another culture. I personally began my medical career as a public health officer on the Navaho Indian reservation, and I see many parallels. There are many lessons to be learned from treating people of another culture which relate to communicating with a community near a dumpsite. One needs to understand the health beliefs of the people for whom one is doing the study. One needs to negotiate a shared-belief model. With the Navaho, when treating a tubercular patient, I had to realize that they believed that their disease was due to some kind of witchcraft or a broken taboo. I thought it was due to exposure to tubercle bacilli, but they really had a point. Eighty percent of the people on the reservation were tuberculin-positive, and most of those did not have active tuberculosis. So we agreed that they would have some kind of Navaho treatment (which I tended to view as being directed towards their compromised immune system) while I went after the tubercle bacillus with chemotherapy. Once that was negotiated, good compliance could be achieved. There are analogies in dealing with community fears about health effects from hazardous waste sites and trying to understand what they think the problem is rather than studying (like the drunk looking for keys under the lamp light) that which can be looked at reliably. The basic admonition here is to pay attention to the hypotheses and concerns of the affected communities. At the minimum it is respectful, at best it may lead you to real health effects which current theory had not foreseen.

In this presentation we will discuss the neighborhood communities because there is always more than one constituency to which we must relate. We will discuss why dumpsite epidemiology is usually equivocal and therefore open to controversy, and we will deal with the emotional pitfalls into which we as epidemiologists tend to fall in dealing with these problems. We will examine these in the context of a case history.

A Case History

We will begin with a case history which illustrates the above mentioned issues so well. Imagine yourself as an oil producer in the early 1940s. War is on its way, and there is a tremendous demand for aviation fuel. A simple way to produce it is to add sulfuric acid to crude oil. Aviation fuel can be decanted off the top, and acid-tarry materials will go to the bottom. There are no technologies for recycling the sulfuric acid, so the acid-tarry material is hauled to the remote oil fields in the foothills of Southern California. A bulldozer comes in, makes a kind of pond with a berm, and then the acid-petroleum sludge is dumped there. There is no one living within miles of the site. Now, 40 years later, suburbs have grown up next to this site, a golf course has been built over some of the ponds, a redwood fence around another, and $300,000 homes have been built all around. People are sold those homes with the promise that condominiums and golf courses will be built in the area. They move in. In the evening, they are sitting in their Jacuzi and suddenly they are exposed to acrid fumes—nauseating, choking irritating fumes that aggravate their asthma. They discover they are living next to a hazardous waste site. Immediately people start breaking ranks. There is a group concerned about health—mostly mothers with young children, some of whom have health effects that they attribute to this site. They are very worried and want to have something done. The local homeowners' association is mostly concerned about the economic issues and tries to quiet these women: "Don't make too much of a fuss because property values will start to go down." The city officials are there. They gave the building permit to allow this to happen. The developer is there. He is the one who allegedly did not tell anyone, even when the workers were complaining of illness while they were building the houses. The broker who sold the houses to everybody allegedly without telling them is there too. Finally there are several government agencies involved, including EPA, and seven different oil companies who deposited materials at the site 40 years ago. The individuals representing the several government agencies often tend to suspect that their jurisdictional concerns will be given short shrift by the other agencies. "The government" is by no means monolithic. This is Orange County, a very conservative kind of area. Some of the residents go to hear Lois Gibbs from Love Canal give a lecture sponsored by an activist political group viewed by many in Orange County as "radical." The women find out that they can get this group to come in and organize their community to get some action. So this very conservative neighborhood now has a "radical group" organizing them and that makes the homeowners association even more upset.

The community pressure is very effective. The Governor's office instructs the Epidemiological Studies Section of the State Health Department that an epidemiological study will be done around this site.

In the public hearings there was great acrimony and disagreement on some very basic points. Was there really an odor problem from this site or were there only a few troublemakers who were complaining about odors which actually came from the adjacent oil fields? Was there really an increased incidence of a variety of subjective respiratory complaints, infections, allergies, bleeding gums, and phlebitis, and was there possibly an increased incidence of cancer and birth defects? We felt that probably we could get an idea of the magnitude of the odor problem. We could get an idea of how common these subjective complaints were, and at the least we could look for a dramatic increase in cancer or birth defects.

Lessons

What do I want to point out about this episode? First of all, the audience. Remember that it would be a mistake to think we are dealing with only one constituency. There were people with very different attitudes. There was no mechanism in the community to talk to the people in the neighborhoods. We are not in World War II America where one had air raid wardens on every block. It really falls to the health department to create a mechanism. Otherwise, there is no way to talk to these people, except through the press. We formed a citizens' advisory committee and published our own newsletter.

The other lesson is that both epidemiologically and toxicologically, no definitive answer was going to come from the study. There was a small sample size: only about 400 adults live there, and only about 60 pregnancies had occurred in the four years since the community had been established. So, there was not much power to show effects of rare outcomes. There was adequate power to look at the subjective complaints and the odor. Every bias known to man was operating here. There was bias in recruitment, since people were starting to selectively move out by the time we did our cross-sectional survey. Obviously there was also going to be bias in recall. There was going to be a problem for cancer, in that the people had only been there for four years; so except for pediatric cancer, we would not have expected there to be an increased incidence of cancer unless there was some promotor that was unmasking things in a very powerful way. It turned out that despite all our good work with the laboratories, it was very difficult to get good estimates of exposure. Airborne exposure was the major concern there, and it came seasonally and in waves during these odor episodes. It was very difficult to get an air sample just at the moment there was an odor. We decided to recruit local residents to collect air samples. That raised a lot of interesting issues such as: Could one trust these people to open a stopcock or would they spike it? Should we pay a professional to come and do it? Later on, the oil companies did indeed pay for someone to be there 24 hrs a day. However, 80% of the time the odor was gone by the time these professionals arrived at the complainant's residence. So, it was difficult to get exposure data. In this particular site there were high concentrations of sulfur dioxide. There was also some concern about windborne arsenic dust from certain areas of the surface. Benzene, which occurs in any petroleum substance, and a substance called tetrahydrothiophene, which has an odor threshold of 0.1 ppb and which was probably responsible for many of the complaints, were also present.

We learned certain things from this experience. Do not be afraid to lay out uncertainities about the data. Once you have become committed to doing a study, you get defensive about the weakness of what you can do. Basically, even in a study like this, uncertainty can be reduced considerably even though it cannot be reduced to nothing. The community will intermittently get frustrated with you because they want to have absolute certainty that there is zero risk. Of course, scientifically, that cannot be done.

It is very important not be be afraid to lay out the milestones of what you are going to do and to calculate the problems and delays which may arise. As a good bureaucrat, you may not want to promise anything to anybody, but basically, what happens then is that people become more and more anxious because you will not specify what is reasonable and what can be done. It is a classic thing to promise step 1, knowing full well that you don't have the resources for steps 2 and 3. When 2 and 3 come, you say, "Sorry, I don't have the resources." People really get upset. It is far better to say at the beginning, "Look folks, we'll go this far and then we are going to have to wait until we can get the contract through. That takes about three months in our state."

Do not avoid contact with distrustful community members. After a particularly angry person has called you a liar three or four times, you tend to withdraw as you do from a difficult patient. You just do not want to deal with those people. But you have to. What you have to do is create some kind of structure where some trust can be established: regular meetings, newsletters, things like that.

What did we do in this case? We decided on a number of things. First, we involved the community activists in those aspects of the study which did not violate their neighbors' confidentiality. The first stage of the study involved a census. Neighborhood workers went out and knocked on doors and handed out a census form. Ideally, it should have been done in a sealed envelope that was to be mailed in to us. Instead, the completed forms were placed in sealed envelopes and returned to us by the workers. We did not want these workers to gather the information by interviews and bring it back, because it was not appropriate for them to learn, for example, whether a couple was married or unmarried. There are issues, even in something as simple as a census, which require confidentiality; and it is possible to involve the community without violating that. We also had to deal

with confidentiality when the results came out. We told people that there would be certain things that we would not reveal. We did not put pins on the map so they could see where the cancer or the induced abortion occurred, because they did not have the right to know that. They could know the numbers, however, after they were collated and analyzed. We also talked to them early on about topics to be covered in the survey. There were a variety of complaints that they brought up. For example, even though it seemed unlikely to us to expect phlebitis, it was on the questionnaire. If we had not dealt with it, we would not have been responding to the community.

The second thing we did was to ask the community to select technically competent representatives to sit in on an advisory committee with us. They chose a pediatric oncologist who lived there and a professor at the University of California, San Diego, who was known to be very concerned about environmental issues. We also decided to include technical representatives from other constituencies so that the oil companies could have some corporate medical officers there. One of them hired a medical epidemiologist to sit on this committee. Representatives from a variety of other bureaucracies that were interested in this also attended. They all agreed that although we would share with them our preliminary results they would not release these until we had a chance to receive their criticisms and revise our analysis, if necessary, to make sure that everyone was satisfied with the thoroughness of the analyses. We agreed that there would be no lawyers present in this group. Indeed, our own lawyers in the health department were very uncomfortable about our talking to all these different people. We decided that we would release the results of the study in sections as they were completed rather than making the community wait until they were all done. The study had four sections that dealt respectively with adult health, pediatric health, obstetrics, and pets. We decided we would not wait for scientific publication and peer review. We believed that we had about the most critical group we could possibly get and that we should not induce an extra delay to gain more scientific credibility. We also decided that we would communicate directly with the community and not through the newspapers. The goal was to make sure that the constituencies knew that the process by which we were analyzing the results was being done with the utmost care. Everyone on the committee promised that they were not going to be leaking results to anyone. It was also important to us to come up against any objections during the analysis phase, rather than publish the results and then have various constituencies come in and start criticizing while the public watched. We wanted to make sure that we dealt with the right issues, and we wanted to make sure that there was clarity and lack of bias in the results.

The procedure was that, once the group was established, we would meet and discuss the results. Then we would mail out the first phase of the analysis. For example, if there was a public summary that would be mailed out to each of the homeowners, the committee would have a chance to comment on that. Then we would meet, discuss the draft, and go back and revise. After a while, committee members got tired of meeting in Orange County all the time and agreed that they would trust us to send the drafts out without having meetings. We would call them, get their comments, and send the revisions to the committee and the community simultaneously. The summaries, put in question and answer format, were mailed to every homeowner in the area. At the same time we sent a copy of the report to the local library so that everybody knew that they could go in and see the entire thing if they wanted to. A little town meeting was held in the town library about two weeks after that.

There was an interesting difference between the kind of comments that we got from the industry group and from the representatives of the community activists. As you would expect, the industry people were concerned that any positive results might be due to confounding or bias, while the community activists were concerned that any negative results might either be due either to confounding or that we had not looked carefully enough. An example of industry's suggestions was that they wanted to impose a more rigorous standard of comparison than the exposed and control communities. Instead, they wanted us to break the exposed community into odor zones to see if there was a dose–response relationship. They asked us not to use the results from our survey of residents about odor, but to use a study done independently by the TRC Company that allowed them to quantify odor zones. Interestingly, the result of analyzing by odor zones was to strengthen the study because there was a very dramatic correlation between *our* questionnaire results on odors and their assessment of odors and a strong dose–response relationship for many of the symptoms that people complained of. We're talking about tenfold differences with p values of 0.0001. But there were many symptoms that community members had suggested be included in the questionnaire that did not show that gradient, so this association was selective. Another example: industry representatives said, "These are households. Their members may influence each other's responses. Your p values are overestimated. These are not independent samples." So we took a random person from every household and looked at the data in that way. The results were the same.

An example of the criticism from the activist group related to a question about birth outcomes which asked about pregnancy results (live birth, stillbirth, spontaneous abortion, etc., followed by an "other" category). The "other" was carefully devised to mean induced abortion. Our community advisory group had suggested that we not ask that directly. There was a slight excess of "other" outcomes in the exposed group, and the concern was that these might be misclassifications or they might have been abortions induced for medical reasons. So, we went back and reinterviewed those people. Indeed, they were all induced abortions. One of them was due to breakthrough bleeding. The rest of them had been

for social reasons. We looked on the map and found that the induced abortions were not related to the proximity of the site.

Conclusion

In conclusion, we had a study which had many results which were quite equivocal and open to argument. But there were parts that we did not think were open to argument. There were a hundred more people than expected complaining of odors in one neighborhood compared with another neighborhood 5 miles away which also was adjacent to an oil field. So, clearly, out of 600 people there was a significant minority that was complaining. Close to 100% of the nearest blocks complained of daily odor compared to an expected 4%. Anywhere from 50 to 100 more people were complaining of subjective symptoms than one would expect on the basis of the control group. But of course that's subjective, so one could say, "they are lying." But even the oil company physicians, when they looked at this clear dose–response pattern, found it hard to imagine that all of this could be explained away on subjective bias. We did not find any difference in cancer or birth defects, but of course we did not have either the power or the follow-up to say much. However, if one looks at the toxicology and our best guess of exposures on the basis of computer modeling of actual measurements of the emissions from the site, one would not expect on the basis of risk assessment to see an additional case of cancer even with 70-year exposure in that population, nor would one expect birth defects. Thus, the toxicology supports what the epidemiology shows.

Because the opinion leaders in this community had some input, had somebody looking over our shoulders, and knew that we were being responsive to their concerns, they were able to accept this for what it was. No, we could not tell them for sure that there was zero risk. Yes, there was uncertainty. But on the other hand, this was about the best effort they could get at this time. We had regular meetings for those who were concerned. Only about 20 out of this community of about 500 to 600 adults regularly attended. They were satisfied that we had made our best effort to answer their questions. So at this time, the health effects of the McColl site are not a controversial issue. The alternative of not having done this correctly and not having been responsive to those community concerns would be a Love Canal-type of scenario where people will be arguing the matter forever.

By addressing the concerns of the several constituencies in this neighborhood and by allowing their technical ombudspersons to review our studies while in progress, we were able to provide information to this community in a way which they have accepted on it merits. Their input improved the quality of our exposure measures, insured the comprehensiveness of the health outcomes surveyed, and provided us with logistical assistance in the crucial early stage of the study. We have been able to move on to provide technical assistance to the engineers as they begin the task of safely removing the wastes.