

Drake Chemical Workers' Health Registry: Coping with Community Tension over Toxic Exposures

ABSTRACT

Background: Programs to communicate health risk information and to protect the health of groups exposed to toxic substances need to tailor interventions to the political, economic, and cultural situation of the at-risk group. In particular, such programs must often cope with exceptional community tension and conflict over these exposures.

Methods: This article uses interviews and written materials to document and describe the state of affairs that led up to community tension over an occupational exposure to a bladder carcinogen. The article describes the planning and design of a program to provide medical surveillance to workers, which also alleviated community concern.

Results: The Drake Chemical Workers' Health Registry coped successfully with community conflict and obtained a high participation rate.

Conclusions: General recommendations include the following: avoid identification with extraneous agendas; know the community and maintain communication; and match the intervention to the evolution of the community conflict. (*Am J Public Health*. 1991; 81:689-693)

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Introduction

Efforts to communicate health risk information and to protect the health of groups exposed to toxic substances are on the rise.^{1,2} However, such activities often take place in situations of intense community conflict.³ The basis of the conflict may be a longstanding debate in a community over the existence of toxic dumps or polluting factories. Or, after notification, lawsuits and citizen action may create new tensions. Political, economic, or cultural tensions can affect both risk perceptions and participation in health protection efforts, yet they are seldom explicitly considered in risk communication activities.⁴ These often focus on strictly technological or medical issues, and are insensitive to the history of the problems, the economic concerns of the community, or cultural issues.

For public health professionals, the first challenge is to develop notification and health protection activities that are tailored to the community situation.⁵ The second challenge lies in professional conduct when remediation may not be available or where resources may not be adequate to the purpose.⁶

This article presents a case study that illustrates some general issues and strategies for public health professionals who must deal with community tensions. The Drake Chemical Workers' Health Registry overcame community conflicts over a toxic exposure problem, and facilitated participation through the resolution of these conflicts. The Registry, one of the first efforts funded through the Agency for Toxic Substances Disease Registry (ATSDR), was created to deal with a major health threat to former chemical workers.

The authors supervise the conduct of the registry, and their assertions should be viewed in that light. Governmental reports and memos from state government, the National Institute for Occupational Safety and Health (NIOSH), and the Superfund of the US Environmental Protection Agency (EPA) document the history of the exposure. Newspaper articles and interviews with community leaders outline the political issues. Finally, community perceptions are reflected in interviews with worker participants, a survey of community residents, and information provided by attorneys.

Background

The Drake Exposure Problem—The Drake Superfund site is located in Lock Haven, Clinton County, a community of 12,000 in rural central Pennsylvania. From 1948 to 1981, specialty chemicals were manufactured at a small plant on the site, first owned by the Kilsdonk Company and later by the Drake Chemical Company. The plant generally employed 20 to 50 persons at a time. Workers were exposed to beta-naphthylamine (BNA), a potent bladder carcinogen, as well as benzidine and other human carcinogens and suspected carcinogens. BNA was banned in Penn-

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sylvania in 1962, but worker exposure probably continued, since BNA may have been a residual contaminant of Broenner's acid, which was produced in large quantities until the plant was closed in 1981.⁷ Studies dating from the 1950s have established the association of occupational exposure to BNA with inflammation of the bladder and bladder cancer.⁸⁻¹⁰ Estimates of relative risk for bladder cancer range as high as 87 percent in these studies.⁸

Community Culture and Perceptions of the Drake Company—The plant had been viewed as an unpleasant, dangerous place to work for many years. Community leaders have noted that residents knew that the plant had problems, but just accepted them. The community needed jobs. People felt that, if anything were really wrong, the government would put a stop to it.

Community leaders, workers, and others describe a high degree of social stratification in Lock Haven. As in other small towns, social position tends to be based on family background and economic circumstances. Social stigma was attached to working at the Drake plant. Based on interviews, Drake workers were generally from rural backgrounds, and many were not well educated. Jobs were generally low paid, and workers were not unionized until two years before plant closure. Former workers, attorneys, and community members have noted that people generally did not work at the Drake plant for very long if they had any other job opportunities.

Plant Closure and Bankruptcy—In the late 1970s and early 1980s, the Drake Company came under increasing state and federal pressure to clean up environmental problems, protect the health of its workers and correct safety violations. A contractor estimated that the cost of site cleanup was more than the company could afford. In its 1981 inspection, NIOSH concluded that remediation of health and safety hazards would require extensive modernization of the plant.⁷ In August 1981, the company filed for bankruptcy and in January 1982 began liquidation of assets.

Emergency Cleanup—In early 1982, the Pennsylvania Department of Environmental Resources nominated the Drake site to the federal Superfund cleanup list. An EPA assessment team declared an emergency in February 1982. The Drake site became the first Superfund site in Pennsylvania and one of the first in the nation. Local officials complained of problems in EPA's communication with the

public throughout the emergency phase. Three incidents during emergency cleanup further eroded public confidence in EPA: release of a sulfuric acid cloud over the town; accidental breakage of a natural gas line on site; and removal by a bomb disposal unit of large quantities of explosive chemicals.^{11,12}

Tension over Health Risks

Formation of Citizens' Group—In 1982, a citizens' group was formed, consisting of community residents and former workers who were increasingly concerned about their potential exposures to toxic substances. This organization educated themselves about worker BNA exposure and pressed for several remedies. They urged progress on the Superfund cleanup as well as state investigation of possible chemical dump sites. They also worked with the Pennsylvania state legislature to appropriate funds for a health surveillance program for workers and residents. This appropriation passed, but was vetoed by the governor.¹³ According to the Lock Haven newspaper, "In one capricious action, the governor has further damaged the confidence of an entire town."¹⁴ The Pennsylvania Department of Health then decided to develop a notification and screening program using existing, but limited, resources.¹⁵

Throughout this period, the citizens' group faced a dilemma. In order to draw attention to the Drake problem, they had to create a stir in the media and maintain community concern. If they had not done so, documentation suggests there would have been no state action, and possibly, there would be no Drake Health Registry today. On the other hand, the group's efforts contributed to conflict in a community suspicious of activism.

Economic Concerns—New events increased community tensions. In 1983, another nearby chemical plant that also used BNA and benzidine closed. A third major local employer closed its doors in 1984. The business community and many residents were worried that attention to the Drake problem would drive away potential investors, according to several interviews and an EPA Community Relations plan developed in 1982.¹⁶ These concerns were taken seriously in a community that had lost three major employers and was experiencing over 30 percent unemployment.

Lawsuits related to exposures and failure to notify workers and townspeople of those exposures, initially totaled \$500

million, and were filed against assets of the Drake company, the second local chemical company, and 14 third party defendants including some of the largest chemical manufacturers in the nation. These lawsuits have yet to be settled.

A public meeting in 1982 with federal and state officials offered townspeople an opportunity to vent frustration over their perception that government was not responsive to their needs. Public health professionals became a target of frustration in part because the health effects of many chemical exposures were not clear, especially for community residents. Officials could not, at that meeting, commit resources to the town or do away with uncertainties about health effects.

First Screening Effort—In 1983, the Division of Environmental Health, Pennsylvania Health Department, developed a two-part health surveillance program for the Lock Haven area: a study of mortality and morbidity among residents of the area surrounding the Drake site¹⁷; and a health effects survey and bladder cancer screening program for former Drake and Kilsdonk employees and their family members.¹⁸ Screening is believed to be an effective early detection measure for those who are at high risk of bladder cancer due to occupational exposure.^{19,20}

Community tension over the program led many workers to decide that they could not participate in the screening program. Media attention to the workers' problem had stressed the dramatic political and legal aspects.¹⁹ Also the social stigma attached to working at the Drake plant, together with the adverse publicity, tended to make many former employees worry about being identified as a Drake worker by participating in screening. Television news clips showed workers entering the screening site; they could be easily identified in a small community where most people are acquainted with each other. Although confidentiality was guaranteed, this publicity caused workers to be concerned about possible consequences for their current employment and health insurance. Hard feelings were also caused by the exclusion from the program of BNA-exposed workers who were not employed at the Drake site. When their company had gone bankrupt, these workers continued to receive a company-sponsored health program—but they viewed it with suspicion. All these factors contributed to the relatively low 47 percent participation rate among eligible workers.

Drake Chemical Workers' Health Registry

Planning and Preparation—By 1986, community tension had declined somewhat. Most parties were frustrated and exhausted over past efforts to address the Drake problem. The Department of Health studies of residents and workers had been completed, and at least some answers were in hand concerning health risks.^{17,18} Also, the focus on BNA exposure may have channeled energies in a positive direction, since it was known to be a problem, and was something that bladder cancer screening could address. At this point, the current health registry was implemented with funding that had become available through the ATSDR. For screening, participants need only provide a urine sample. Screening consists of a Pap cytology, urinalysis to check for hematuria, and an experimental test, Quantitative Fluorescent Image Analysis.²⁰ A positive screen is followed by diagnostic procedures. All screening and diagnosis is provided at no charge. Details of the medical protocol for bladder cancer screening are presented elsewhere.²⁰

As neutral third parties from out of town, the registry researchers were to some degree protected from community tensions. Initially, however, the program was not prepared to deal with community conflict, and it rapidly became clear that these forces might ruin the new effort unless several steps were taken to defuse tension. The program developers consulted with Department of Health and NIOSH sponsors, visited the nearby Port Allegany asbestos program,²¹ and learned from past experience. Six steps were taken based on this consultation. They have proven to be extremely important to program design.

- First, implementation was preceded by thorough discussion with community leaders about the history of the Drake problem and the current feeling of community members. By talking with such leaders, the program was able to avoid linkage to past problems and maintain credibility.

- Second, the program immediately established a community advisory board that included representation from affected parties, such as the citizens' group, as well as respected leaders, such as the Chamber of Commerce. This step was only possible because tension had diminished. These leaders had to some extent arrived at the conclusion that they needed to solve a mu-

tual problem. The names on the advisory committee sent a signal that the screening program was not allied to any one faction.

- A third step was the creation of a workers' advisory committee. This committee was designed specifically to give former Drake workers a say in the details of system design and creation of notification materials. Also, the committee consented to pretest the notification materials, to make sure that they were understandable and would motivate workers without producing dysfunctional fear. In addition, the worker committee assisted the program in contacting the former Drake workers whom they knew, and constituted an "early warning system" in case any materials or operations created dissatisfaction among workers.

- A fourth step was notification of the medical community, well in advance of any media publicity, about the nature of the screening activity. Two goals were addressed by this communication: the physicians were notified about the bladder cancer problem, so that they would be alerted to signs and symptoms; and the physicians were also assured that the program would not be practicing medicine. Although free diagnostic services were provided if workers tested positive, the screening itself was aimed strictly at early detection and health education activities that were not within the scope of usual medical care.

- Fifth, it was necessary to hold the lawsuit issue at arm's length, while disposing of worker inquiries about the suits in a responsible manner. When screening staff encountered questions from workers or their families about lawsuits, they stated that the screening program had nothing to do with the lawsuits, and questions should be directed to workers' attorneys. This policy was explicit from the beginning, so that no staff member became embroiled in an extraneous issue or offered misleading advice. This was the responsible course as well, since workers and their families have sometimes misunderstood the purpose of screening programs and have expected legal help from the program without ever being directed to the proper source.

- A sixth step preserved the program's neutrality while removing possible interference by the lawsuit in health protection. Law firms involved in other toxic exposure lawsuits have often advised their clients not to participate in screening. The Drake program was fortunate in that a single law firm handled the suits. The Drake program established low-key communica-

tion with this firm. The firm mailed a letter to all its Drake clients, stating that the screening program had nothing to do with their lawsuits, but that clients should participate in order to protect their health. A dedicated paralegal professional was primarily responsible for convincing the firm to make this decision.

Notification and Recruitment System—The registry team planned, not for haphazard communication, but for a system of notification and recruitment in which former employees would receive information through many channels. Three major strategies for recruitment were utilized: 1) a media campaign; 2) two mailed notification letters; and 3) personal contact by the clinic coordinator.

Within a 50-mile radius of Lock Haven, an intensive media campaign announced the availability of the free screening program during the fall and winter of 1986. Follow-up media messages have been used less intensively ever since. Public service announcements stressed the benefit of obtaining screening, as well as the ease of screening, preparing workers for the notification, and recruitment efforts that followed. By this point, the more sensational aspects of the Drake story were no longer news. The media were ready for a new Drake story, but the only available story was the importance of screening.

In media messages, an explicit appeal was made to family members and friends of workers, under the assumption that someone in the family would be concerned and would get the person into screening. Interviews with participants later revealed that this strategy was useful. Sixty-three percent had discussed the screening with someone, generally family members (36 percent of participants) friends (12 percent), or other Drake workers (11 percent). Of those discussing screening, 79 percent received encouragement to participate, and 39 percent said they would not have come for screening without such encouragement.

In addition, community members were now ready to commit themselves to support of the screening program. Local religious leaders agreed to urge their parishioners to participate. All local merchants agreed to place copies of the program pamphlet at the front of their offices and buildings (except for a national chain with a policy against such practices). Note that this could not have been accomplished except that working with the community leaders had produced a diminution of the community polarization.

The notification letters were mailed to the person's last known address. If no response was forthcoming within three weeks, a second letter was sent. Letters were mailed in batches over time, so that worker questions could be answered, fears alleviated, and appointments made on a timely basis. The ethics of this decision are clear. If the screening coordinator had been overwhelmed with inquiries, people would have waited for service while their fear and helplessness increased, and participation would have suffered in consequence.

Notification letters and all other materials were written at the most basic reading level and were pretested on volunteer workers. Enclosed with the letter was a pamphlet that provided an official description of the program and addressed many questions, fears, and concerns. Also enclosed was a flyer with an old picture of the plant. Even illiterate workers could see this flyer and the letter, realize that something important had come in the mail, and ask someone to read it. The clinic coordinator initiated personal contact if workers did not respond to either letter. In other public health screening efforts this sequence produces high response rates and saves labor intensive outreach.²² Screenings were conducted in a private location, at hours convenient to participants, and some screenings were conducted through home visits.

Workers tend to have many other pressing problems besides risk for bladder cancer. Our screening coordinator has helped people find jobs, deal with the legal system, obtain food stamps, and meet many other needs. This commitment has built a relationship of trust and maintained their involvement in the registry.

Effects of the Health Registry on Community Tension—Of living cohort members that have been notified by mail, 81 percent have chosen to participate, while only 7 percent have positively refused to participate at any future date. Three bladder cancer cases have been discovered among living participants; however, these were discovered through means other than the screening program. In addition, 26 individuals have had positive screening results and are being monitored closely for abnormal cytologies. Most participants return for annual screenings, while those with positive screening results are asked to return for semiannual screening. Over 90 percent have returned for screening.

Positive effects on the Lock Haven community were evident from the re-

sponse rates of community surveys conducted before and several months after the start of the media campaign. The two community surveys used essentially the same methods of mailings with telephone follow up. Before the campaign, response rate was highest, at 70 percent, in the 50-mile catchment radius around Lock Haven, and lowest, at 30 percent, in Lock Haven itself. Many Lock Haven residents said they simply did not want to become involved with anything related to the Drake issue. In contrast, a 90.9 percent response rate was obtained throughout the area, once the media campaign had been in place for several months. Eighty-one percent had heard or read about the program. In addition, 84 percent of residents at follow-up said they would have participated in screening if they had been former workers, and 18 percent said they had talked about the screening with a former worker.

Conclusions and Recommendations

Public health professionals can encounter substantial community conflict when toxic exposures occur.^{3,4} However, our experience offers some recommendations to address community conflicts in a positive way.

- Avoid identification with extraneous agendas. Public understanding of the value of prevention is not automatic. It is all too easy, therefore, for communities to perceive the programs as furthering other goals that may be feared or that generate conflict. In Lock Haven, the screening program was deliberately separated from the lawsuit agenda and from the employment agenda. Also, the town had lost confidence in state and federal government. It was necessary to choose a new organization to conduct the research.

- Know the community. Facile assumptions about community dynamics will doom this kind of program to failure. It is essential that the manager of notification and screening programs know the community or worker group well and maintain communication.

- These crises evolve over time. Different kinds of intervention may be needed at different points in a community's reaction to a toxic exposure. At early stages a range of needs may exist, from a carefully planned emergency response, to responsive, truthful communication that respects community concerns. Once a crisis has died down, it may be easier to shift the community focus to problem solving.

These recommendations appear to be generalizable to other situations involving community responses to toxic exposures, based on other case studies and surveys.^{1,3-5} While the specific strategies employed in this case might need adaptation to other local circumstances, they are based on good practice in health education and public health, generally.

What is noteworthy about the toxic exposure area, however, is how often these recommendations cannot be implemented under current policy and guidelines. For example, when affected communities feel that inadequate attention or resources are being given to their needs, it is all too easy for officials to be identified with other agendas.⁶ A central dilemma for health departments is to be responsive to community concerns and needs, while retaining objectivity about the extent of health problems and the need to allocate limited resources carefully.⁶

When state or federal agencies must intervene, perceived time pressures sometimes mean that the community is not sufficiently understood prior to implementation. Contractors for community interventions are frequently chosen on the basis of a bid, and not with regard to their credibility in the relevant community. National risk communication and community relations guidelines for Superfund and for ATSDR are improving. However, they do not address the need for continuity of informal communication with affected communities. Furthermore, the technological focus in cleanups and the medical focus in registries often work to discount concerns about community impact. As long as crises of confidence continue to develop in affected communities, there will be a need for better policy and practice in risk notification and health protection. □

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