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COMMUNICATING RISKS AFTER EXPOSURE HAS ENDED: FORMER WORKERS' PERSPECTIVES ON PCBs

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Abstract

While the importance of worker notification has been widely recognized, little attention has been paid to social and psychological contexts in which worker notification occurs, especially after the exposure has ended. This study explores workers' perspectives on exposure to polychlorinated biphenyls (PCBs), a toxic material whose manufacture in the United States ended in 1977. Four focus groups were conducted with former workers (n = 29) who were exposed to PCBs. Verbatim transcriptions were analyzed. Participants considered living in the PCB-contaminated community more dangerous than handling PCBs on the job. While they firmly believed that PCBs in the environment caused serious health problems, participants expressed doubts about the toxicity of PCBs in the workplace. Both beliefs undermined the value of worker notification about occupational exposure to PCBs. A long-term relationship between workers and researchers would provide opportunities to cultivate better understanding of the hazard and facilitate the process of worker notification.

Keywords

workers' right to know; worker notification; focus groups; qualitative analysis; risk communication

Informing workers about occupational hazard exposure (i.e., worker notification) is not only a necessary health protection measure but also an ethical imperative [1–4]. Knowledge of occupational hazard exposure may facilitate safety practices [5] and may influence precautionary medical screening [6]. Although the importance of communicating risks associated with occupational hazard exposure has been recognized, research is still scarce in some areas [1, 7]. The small literature on worker notification has tended to focus on the packaging of the information [7–10], logistics of conducting worker notification [1, 11–13], and workers' post-notification attitudes and mental health [7, 14, 15]. Relatively little has been discussed about the context in which worker notification occurs [16, 17] and its implications for the communication process.

Houts and McDougall [16] emphasize the importance of understanding the psychological contexts of worker notification, which include pre-notification knowledge, perceptions, and

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attitudes concerning health risks addressed by the notification. These are formed by shared and unique life experiences that workers have had. Needleman [17] proposes the concept of worker notification not as a discrete event but rather as a dynamic, continuous process that is firmly situated in the local community, history, and politics. Houts, McDougall, and Needleman all point out that workers who receive notification are not blank slates and urge that worker notification be considered in specific psychological and social contexts. However, the concerns of those who produce notification materials, even of those who promote "cultural" considerations, seem to be narrowly focused on workers' native language, literacy level, and race/ethnicity [8, 13, 18].

In this article, we explore psychological contexts in which a specific worker notification occurred: risks associated with occupational exposure to polychlorinated biphenyls (PCBs), which ended in the 1970s. First, we discuss the unique challenges of communicating risks resulting from past occupational hazard exposures. Next, we present an analysis of focus group interviews that revealed some psychological contexts in which workers received the information about their past occupational exposure to PCBs. Finally, we propose a strategy to improve risk communication between occupational health researchers and workers who were exposed to hazardous materials.

CHALLENGES IN COMMUNICATING OCCUPATIONAL RISKS AFTER EXPOSURE HAS ENDED

Communicating the results of occupational cohort studies often poses special challenges. A primary one lies in workers' perceptions of the relevance of communication contents. Cohort studies are often conducted using archival data from workplaces and information from disease registry systems and death certificates. As a result, workers may not know they were in a study and may not feel particularly engaged when they receive study findings. In addition, occupational cohort studies typically take many years to produce results. By that time, the information may not seem relevant: workers may have changed jobs or retired, the hazardous material may no longer be used, and/or the company may have closed. For individual workers who have been healthy since the exposure, the risk may seem minimal [19].

While these situations suggest that worker notification may be received with indifference, other situations may elicit negative responses. For example, the hazardous material studied in the occupational cohort may have been also recognized as an *environmental* hazard. Because risk communication in community settings is typically more active and organized than in occupational settings [20], workers may have substantial knowledge of the hazard from various sources such as mass media, the Environmental Protection Agency (EPA), and community activism even before worker notification. In such situations, worker notification will be received with heightened awareness and preconceptions of the hazard. Also, the time lapse between exposure and notification could create mistrust of those who send the notification [21], especially if the hazardous material has been known to workers from other sources.

According to the risk perception literature, certain characteristics of occupational hazard exposure lead people to identify it as an “unacceptable risk” [22–24]. For example, occupational exposure to a chemical is often unobservable, and health consequences (e.g., cancer) are often dreadful. The exposure may feel involuntary because it was part of the job. Moreover, because the exposure has already ended, reducing or eliminating exposure is no longer possible. Risk perception theories suggest that these characteristics of occupational hazard exposure would create strong, negative affective reactions among exposed workers. One key goal of worker notification for past hazard exposure is to ensure workers’ satisfaction with the information [25]. This may be hard to achieve given the unique circumstances of worker notification coming out of occupational cohort studies.

The current literature offers little insight into the psychological contexts in which workers receive notification, especially when hazard exposure has already ended. Therefore, it is not well understood how to conduct risk communication under such circumstances. As a starting point, we present an analysis of focus group interviews with workers who were exposed to PCBs in the past. PCBs were commonly used in manufacturing electrical capacitors, but their manufacture in the United States was banned in 1977. We explored former workers’ concerns regarding PCB exposure as they received fact sheets describing findings from two occupational cohort investigations. By exploring psychological and community contexts surrounding PCB exposure, this paper provides insight into effective approaches to worker notification after exposures have ended.

METHODS

Notification Materials

The current study is part of a project to evaluate worker notification materials that NIOSH provides to study participants. The notification materials (fact sheets) used in this study were developed based on four academic journal publications on PCBs’ health impacts, all prepared by NIOSH researchers. One publication focused on breast cancer incidence and mortality [26], and the others on all-cause mortality [27–29]. All four were cohort studies of workers who had been employed in three manufacturing plants before 1977. For the breast cancer investigation, between 1998 and 2000 NIOSH asked former workers to complete a questionnaire. The all-cause mortality investigations were conducted using existing records only. The investigations found that PCB exposure was associated with mortality from various types of cancer for both men and women [28] and that for women, PCB exposure was associated with mortality from certain neurological diseases [27, 29] but not with breast cancer risk [26].

Fact sheets were prepared to communicate these findings to all living workers in the studies. Along with information about NIOSH and the Centers for Disease Control and Prevention (CDC), the fact sheets typically consisted of the following sections: *Summary*, *Why we did this study*, *How we did the study*, *What we found*, *What you should do*. As an example, one of the fact sheets is shown in the Appendix. Other fact sheets summarizing various studies NIOSH has conducted can be found online (http://www.cdc.gov/niosh/pgms/worknotify/).

Participants and Data Collection

As part of the evaluation effort, we invited a sample of workers to participate in focus group interviews to discuss the content and design of the fact sheets. Data were collected in four focus group interviews: two were conducted in Massachusetts and two in Indiana. In each location, randomly selected former workers in manufacturing plants that had used PCBs (n = 200 in Massachusetts, n = 160 in Indiana) received an invitation letter. We made follow-up phone calls until 32 former workers agreed to participate in the four focus groups. Of those, 29 actually participated. Table 1 summarizes the characteristics of the participants and the contents of the fact sheets for each focus group.

Two focus group interviews were conducted in each location: one with the breast cancer study participants and the other with the mortality study participants (Table 1). The participants in the breast cancer focus groups were all women; the mortality focus groups included both men and women. Participants in each focus group had worked in the same plant but not necessarily at the same time. The length of employment ranged from 6 months to 46 years. All participants lived in the area near the plant where they had worked. In order to protect their identity, detailed demographic characteristics of participants were not systematically collected. However, the following information was obtained from the conversations during the focus groups. Most but not all participants directly handled PCBs during their employment. In each group, some participants had had cancer, others had not. Each focus group lasted 75 to 90 minutes, and participants were compensated for their time and travel. The focus group interviews were audio-recorded after informed consent from all participants was obtained. The recordings were then transcribed verbatim and analyzed.

The fact sheets were mailed prior to the focus group so that the participants had a chance to review them. Each focus group had a main moderator and co-moderator who were not involved in either the epidemiologic studies or development of the fact sheets. The main moderator facilitated the discussion by asking for the participants' reactions to each section in the fact sheet. After asking, "What do you think about the content of [*section*]?" the moderator let the participants talk freely and respond to each other's comments. The co-moderator observed the discussion. The original purpose of the focus group interviews was to obtain feedback on the readability, wording, design, and contents of the fact sheets. However, participants in all four focus groups engaged in extensive conversations on a wide array of topics surrounding PCB exposure, shared personal stories and experiences, and expressed various perspectives and concerns. These unstructured conversations provided an unexpected but invaluable opportunity to explore the contexts in which these participants received their worker notification. This article's analysis focuses on these discussions about PCBs.

Data Analysis

Verbatim transcriptions of the four focus group interviews were used for thematic analysis [30]. The first two authors conducted the analysis. We read the transcripts closely, identified themes separately, and then jointly developed an initial codebook. We then independently coded the texts. Next we discussed the coded segments, refined the codebook, and identified major themes and their dimensions by constantly comparing similarities and differences in

the coded texts. We repeated this process until no further major themes emerged from the transcripts. We started with two *a priori* general categories, hazard exposure and health consequences, because these are not only fundamental elements of epidemiologic investigation but also central concepts in risk perception [23]. After coding segments under these two broad categories, we identified subcategories such as sources of exposure, types of health consequences, affirming and denying opinions (e.g., “PCBs cause cancer” and “PCBs do not cause cancer”), and varying degrees of confidence in assertions. While we attached importance to repeated themes across different focus groups, we also carefully gleaned opinions that were expressed infrequently. By design, this analysis does not intend to generate statistics generalizable to any larger cohort (e.g., percentage of workers who had positive responses to the fact sheets, number of utterances under a certain theme). Rather, our analysis focused on identifying the breadth of responses within each theme and the patterns in the combinations of ideas. All analyses were conducted on NVIVO v.8 [31].

RESULTS

Occupational and Environmental Exposures to PCBs

The most prominent theme across all focus group interviews was the belief that the entire area surrounding the former plant was badly contaminated with PCBs. Participants saw the company as the source of environmental contamination, but they did not consider it responsible for their occupational exposure. Clearly environmental exposure through the air, water, and soil was the foremost concern to the participants, and occupational exposure had less importance:

> I haven’t worried about working at [the company]; I’ve worried about living near the river and seeing all of those people having cancer. [Breast Cancer FG1]

Even though the fact sheet they received addressed only occupational exposure to PCBs, the discussion in all focus groups gravitated toward environmental contamination and its health impacts on area residents.

> If you’re studying the building you worked in, you’d think that the whole area would be studied, you know? Whatever was coming out of that building must have affected everybody in the neighborhood and everything, you know? [Breast Cancer FG1]

The strong concern about environmental contamination in the community was accompanied by the participants’ skepticism about the company’s practice of chemical disposal after PCBs were banned. Many participants were aware of past dumping sites and their current uses—for example, as schools, parking lots, and farm fields. They expressed the fear that many people in the area continue to be exposed to PCBs because of careless disposal practices.

> [Children in the area] are with these diseases because of the environment of where they live and how [the company] chucked this stuff. I mean, they’re not doing it right; they’re cheating and yet they’re getting paid for it. That’s not right. [Mortality FG1]

While environmental contamination was discussed with frustration and condemnation of the company, the participants discussed occupational exposure with a strikingly different tone of voice. They made allowances such as “we didn’t even think about [health impacts of PCBs], you know, because people didn’t worry about chemicals or anything” [Breast Cancer FG1]. By using “we” sentences exclusively (e.g., “we didn’t know”) as opposed to “they” sentences used in describing environmental contamination, the participants described occupational exposure to PCBs as the consequence of their own actions, lack of precaution, and lack of knowledge.

> We didn’t worry about mops or anything like that, because we just didn’t know. We didn’t worry about [wearing] gloves. [Breast Cancer FG1]

Some participants considered occupational exposure as an inevitable part of the job or even a fair trade-off for having a job:

> I worked here, and I worked right here with all that stuff. We did things that we probably should not have done, you know? (Another participant: But we had to do it.) Yes, we had to do it, and we was glad to have that job. We’d give anything if we could have that job back in [the town] now. [Breast Cancer FG2]

Throughout the four focus groups, only one participant complained that the company did not notify him about potential risks of PCBs:

> I know that if I had that information before I went to work there, I probably wouldn’t have went to work there. They asked me if I was allergic to oil, that was it. [Mortality FG2]

Conflicting Beliefs about Health Impacts of PCBs

Participants had seemingly contradictory beliefs about the impact PCBs have on health, depending on the source of exposure. When they were discussing environmental contamination, they were convinced of the harmful impact of PCBs. In fact, participants repeatedly referred to the high incidence of cancer and other serious diseases in the area as evidence for the toxic nature of PCBs: “No one knew what it was until people started getting sick” [Mortality FG1]. They insisted that now everyone knows PCBs in the environment cause a number of serious diseases. To reinforce the credibility of this, they recommended that researchers collect information from physicians in the area:

> I think the different types of cancer that PCBs cause and what’s known around here [should be included in the fact sheet]. You [the moderator] could even ask the doctors because it’s common knowledge around here that PCBs cause problems. [Mortality FG2]

However, when participants discussed occupational exposure to PCBs, many expressed doubts. Across all focus groups, arguments were made against the health impacts of PCBs. Some stated that they themselves had worked with PCBs but never had cancer and that they knew other former workers who lived a long, healthy life. Even the consequences of direct exposure to PCBs on the job were discussed with skepticism.

> Well, I don't know how quickly [PCBs] went through your skin. I'd question that, I mean, because I was touching that all the time and I never had any irritated skin (Another participant: I didn't either.) or anything like that, and you're washing your hands in [PCBs] and we're eating it…. If there was no irritation or anything, then it wouldn't bother us or have any effect on us if we weren't even feeling it. [Breast Cancer FG2]

Others noted that people who had never worked with PCBs still died of cancer. Specifically, they pointed out various causes of cancer other than PCBs, such as family history and personal habits (e.g., smoking and drinking). One participant who had worked with PCBs and did have breast cancer attributed her disease to family history and "wouldn't blame PCBs at all" [Breast Cancer FG2]. Some participants were skeptical about whether epidemiologic studies could even establish a causal link between PCB exposure and disease.

> Actually, can they [researchers] tell if it comes from PCBs? I mean, there are people that have all of these [diseases] that have never been around PCBs, and so they can't say that, you know, this actually caused it because there's no real way to prove it. [Mortality FG1]

Reactions to the Studies, Science, and Worker Notification

As described above, participants firmly believed that PCBs were toxic in the environmental context but at the same time were ambivalent about PCBs' health impacts in occupational contexts. Yet both views seemed to prompt workers to undervalue epidemiologic studies. On one hand, because the participants believed that the harm of PCBs was definite and already well known, they did not see the need for further epidemiologic studies. Instead, they pointed out that the fact sheet was inaccurate because it failed to mention many serious diseases that *they knew* were caused by PCBs. On the other hand, because many participants were not entirely convinced that the causality between occupational exposure to PCBs and diseases could be proven, even a positive comment about the risk communication material was quite reserved:

> Well, somebody feels that it's important if they're doing this whole study. Statistically, I mean that's the only benefit there is from it. [Mortality FG1]

Some participants held a more cynical view of government agencies and their motivation to do research: protecting the company from lawsuits and keeping the government in business. These views were expressed across all focus groups. In response to the moderator's final question, "What do you think the main message of this [fact sheet] is, and what does it all mean? What do you think?" one participant expressed his strong frustration:

> You want my opinion? I think that all of this paper [the fact sheet], you cut down trees and it means nothing…. So no matter if they let you know what the statistics are, how many people died of this, how many died of that—it means nothing. The place is closed. We've all been there. This is all wasting trees for nothing…. If you get sick, go to a doctor and take care of it. You're not going to be able to sue anybody. (Another participant: Because you can't prove it.) It's done. That's it. So what are we gaining here? Nothing! Nothing! [Mortality FG1]

Worker notification was perceived as minimally valuable if the information reaches the exposed workers decades after the occupational exposure was over. No action could be taken to reduce their exposure or even to hold anyone accountable.

Despite these negative reactions, the participants still wanted to know about research regarding PCBs' health impacts. With frustration and confusion, many participants asked why it had taken so many years to receive the information about PCBs:

> It says 1977 [when PCBs were banned]. Why have they taken so long to do a study on this? What they have been doing—up until now what have they been doing? [Breast Cancer FG1]

> It was just too long in between getting the information. [Mortality FG1]

These comments were followed by a call for more frequent communication between researchers and former workers. There was no difference between the breast cancer and mortality focus groups in expressing this need for more information, even though the breast cancer study participants had filled out a questionnaire about a decade earlier whereas the mortality study participants had not.

DISCUSSION

Using focus group interviews, this study explored psychological contexts in which worker notification materials on PCBs were received. Our analysis revealed that the participants processed environmental and occupational exposures quite differently. They considered that PCB exposure through contaminated water, soil, and air was more dangerous than exposure to the same chemicals on the job. Further, they strongly believed that environmental exposure to PCBs caused serious health problems and that this was a well-known fact. They condemned the company for their contaminated community. In the context of occupational exposure, however, the participants took responsibility for their exposure to PCBs and questioned whether PCBs had serious health consequences or if the causality could be known for certain. Here we attempt to make sense of these opposing perceptions of PCBs and discuss strategies for situating worker notification practices in psychological contexts.

Making Sense of the Contradictions

The seemingly contradictory beliefs about the health impacts of PCBs can be in part explained by the different nature of environmental and occupational hazard exposure. Our focus group participants, who all lived in the contaminated area, discussed environmental exposure as the community's problem but not necessarily as each individual's personal problem. In contrast, the participants perceived that occupational exposure to PCBs was definitely their own problem. After all, they are the ones who handled the chemical without gloves. The different levels of personal relevance may have led to different beliefs about the health impacts of PCBs from different sources.

Researchers assess risks associated with hazard exposure as risks for a group, not for each individual. If the risk of a negative event is expressed for a group (e.g., "increased risk of cancer among those who lived in the community at least for six months"), individual

members of the group tend to discount their own personal chance of experiencing the negative event. This is a phenomenon known as self-invulnerability or perceived personal immunity [32]. It is likely that the focus group participants estimated their own personal risk of developing cancer as lower than that of others in the community. Because of this perceived personal immunity, they can afford to believe that PCBs cause serious health problems to area residents.

In addition, environmental exposure is *ongoing* through PCB-contaminated water, soil and air; therefore, in theory, something could be done to reduce the exposure and resulting health problems. Under these conditions, people have incentives to believe that PCBs cause fatal diseases: if PCBs' health impact is truly dreadful, someone—the company, the government—might do something about it.

In contrast, occupational exposure to PCBs has two characteristics that may have made it hard for the former workers to accept the link between PCBs and serious health problems. First, because the exposure on the job ended a long time ago, they cannot do anything to reduce the harm. Second, these former workers felt responsible for their occupational exposure to PCBs. This shift of responsibility from the company to individual workers was reported in an ethnographic investigation of blue-collar workers [33]. Through in-depth interviews, Zoller pointed out that the workers held identity norms that gave them positive self-image and at the same time facilitated their consent to occupational hazard exposure [33]. One such identity norm was the belief that a good worker will endure demanding work conditions, including hazard exposure, and not complain. Another relevant identity norm in Zoller's study is that workers implicitly accept that they trade their health for wages and consider job-related hazard exposure as part of the deal. Our findings suggest that even after they left the job, former workers are still motivated to maintain their positive self-image as workers by taking responsibility for occupational hazard exposure and not blaming the company.

The belief that occupational exposure was the consequence of one's own act (e.g., "We did something we probably shouldn't have done.") may make it difficult to accept that their occupational exposure can lead to dreadful outcomes. Because the former workers knew that the exposure definitely occurred in the past and cannot be changed, they questioned dreadful outcomes in order to resolve the cognitive dissonance [34]. Similar results have been reported in a number of studies in the health psychology literature: the higher the personal relevance of health information, the less convinced people are by the information [35–38]. For example, smokers are more skeptical of the risk for lung cancer than non-smokers. Similarly, because occupational PCB exposure is highly personally relevant to these former workers, they expressed doubts about the link between PCB exposure and serious health problems.

In addition to using these psychological mechanisms, we can apply a broader perspective to the focus group participants to help us further understand the contradictory beliefs about environmental and occupational exposure. Zoller [20] spells out how workers and area residents have been alienated from each other in discussing the impact of industry on health: the workplace is considered a private, self-contained entity in which workers trade their

health for pay. This view removes workers from environmental health advocacy even though they may be exposed to the same hazard more severely on the job than are area residents.

Zoller's discourse analysis [20] on the workplace as a private sphere suggests that our focus group participants were caught in a contradictory position as former workers and as long-term residents of the contaminated community. As citizens, they condemned the company for environmental contamination and the serious health problems resulting from it. As former workers, they took responsibility for occupational exposure and questioned PCBs' health impacts, thereby weakening their own voice as citizens. The dualism and alienation that Zoller [20] pointed out exist not only between workers and area residents but also within workers who live in the area and thus stand at the intersection of occupational and environmental health. As Morse and Parker [39] argue, workers and citizens need to come together to demand a safer and healthier environment for all.

The disjunction between citizens and workers is reflected in risk communication literature as merely the lack of attention to occupational hazard. Risk communication researchers can facilitate the partnership between workers and citizens by investigating the way risks associated with occupational hazards are communicated, just as they have with environmental hazards. Because the risk communication literature has close ties to environmental advocacy, filling this gap in the literature will make workers' health a part of this effort and thus strengthen the voice of both workers and citizens.

Study Limitations

This study analyzed former workers' perspectives on PCB exposure using data from minimally structured focus groups discussions. These discussions elicited participants' reflections on the topic within a social context and therefore provided views that were socially acceptable. While this to some extent ensures that our results are not influenced by a few extreme opinions, the data may be lacking subtle ideas that might have been obtained in individual in-depth interviews.

We took advantage of the rich data obtained in the focus groups to investigate psychological and community contexts of worker notification. However, because the focus groups were originally designed to obtain information about the wording, design, and topics covered in worker notification materials, at least two additional limitations should be acknowledged. First, because the participants received the fact sheet beforehand, focus group discussions may have reflected what was in the fact sheets. Participants of two focus groups received information about breast cancer, and the other two groups received information on all-cause mortality. We compared our findings by health outcome and did not find any systematic differences, and thus we are not concerned about specific contents of the fact sheets influencing the findings. Second, the moderators were not instructed to probe when participants discussed PCBs exposure in general. As a result, the data are not as detailed as they otherwise would have been, and we did not reach theoretical saturation (i.e., a data-collection stage at which additional interviews no longer provide new information). While relatively consistent findings throughout the four focus groups give us confidence in our findings, other themes might have emerged if data collection had continued.

Individual characteristics (e.g., age, sex, cancer survivor or not) of the participants were not systematically collected but were gathered from conversations in the focus groups. Even though the invitation was sent to randomly selected former workers, the representativeness of the focus group participants within the larger occupational cohort could not be assessed. In addition, because the transcripts did not identify multiple comments made by the same individual, we were not able to connect individual characteristics to each comment spoken. This limits our ability to investigate various themes in light of personal contexts. Our findings should be regarded as starting points for future investigations.

Implications for Practice

The focus group findings support Houts and MacDougall's assertions [16]: workers are not blank slates when they receive worker notification materials, and the psychological and social contexts in which worker notification occurs create the meaning of the communication. As we summarized and examined above, our participants did have substantial knowledge and opinions about environmental PCB exposure. Further, their comments indicate that some underlying mechanisms made it difficult for them to process information about occupational exposure and associated risks. In addition, for the workers, the time lapse from exposure to notification evoked some frustration and cynical views of government epidemiologic studies. These findings also support Needleman's notion that worker notification is part of an ongoing process of a community's coping with hazard exposure [17].

Part of the purpose of communicating risks associated with prior occupational exposure is for workers to feel satisfied that they have been adequately informed about their risk [25]. Our findings clearly suggest that former workers are unlikely to feel satisfied if their current main concern—in this case, their PCB-contaminated community—is not addressed. A meaningful risk communication starts with recognizing the specific local contexts and histories. This must happen before developing communication plans so that worker notification is not perceived as out of touch with workers' lives.

Occupational cohort studies can be conducted without active involvement of those whose health is investigated. However, the separation makes worker notification seem "out of the blue." One way to avoid this is to apply the community-based participatory research (CBPR) paradigm [40, 41]. CBPR aims to "increase the value of studies for both researchers and the community … through the use of shared knowledge and valuable experiences" [39, p. 1]. This could be achieved if researchers and study participants maintain communication throughout the duration of the study, which could be many years. During this time, scientists could not only learn about local contexts surrounding the hazard exposure but also help workers gain knowledge regarding those hazards. This will make the subsequent worker notification more relevant to the workers [42]. While the actual implementation of CBPR has a number of unresolved challenges [40, 41], the spirit of sharing knowledge and experience must be the foundation of worker notification.

A major barrier to maintaining long-term communication between researchers and study participants, and CBPR in general, is the cost [40]. Epidemiologic research projects almost never budget the necessary resources for keeping communication channels open over a long

time period. Communication strategies need to be discussed at the beginning of a research project, and appropriate resources should be allocated. Low-cost strategies such as using the Internet and social network systems should be explored.

Long-term communication between scientists and workers could provide an opportunity for workers to express their concerns. Their shared concerns will help researchers to frame particular findings in context. At the same time, by being heard by researchers, workers would enhance their sense of self-worth. This becomes important when the final result is communicated. The self-affirmation theory [34] suggests that if people are given opportunities to affirm their self-worth, threatening information (e.g., their chance of developing cancer) is processed with less denial and fewer biases. A successful process of worker notification can thus be achieved through a long-term relationship between scientific and worker communities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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NOTES

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Table 1

Characteristics of Focus Groups with Former Workers Exposed to Polychlorinated Biphenyls (PCBs)

	Focus groups on breast cancer incidence		Focus groups on mortality and causes of death	
	Focus group #1	**Focus group #2**	**Focus group #1**	**Focus group #2**
Location	Indiana	Massachusetts	Indiana	Massachusetts
Date conducted	September 29, 2009	April 23, 2009	September 30, 2009	April 22, 2009
Number of participants	5 (all women)	9 (all women)	8 (5 men, 3 women)	7 (3 men, 4 women)
Job tenure	3–9 years	2–38 years	6 months–40 years	6 months–46 years
Major findings presented in fact sheets	No increase in breast cancer incidence associated with exposure to PCBs		Deaths from some neurological diseases associated with exposure to PCBs among women Deaths from brain cancer associated with exposure to PCBs Deaths from myeloma and cancers of liver, ovary, prostate, and stomach associated with greater exposure to PCBs	
Published studies on which the fact sheets were based	Silver et al., 2009 [26]		Steenland et al., 2006 [29] Prince et al., 2006 [27] Ruder et al., 2006 [28]	

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