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Methodologic Issues in Risk Communications to Workers

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Until the late 1980s, epidemiologists in general did not *individually* notify subjects of the results of epidemiological studies. Now that they are beginning to do so, the question arises of how best to notify those involved. In general, the methods, the processes and the policies related to effectively communicating risks to workers have not been thoroughly examined in the scientific literature. This is especially true in situations where workers have already experienced the exposures that led to increased risks for disease.

The recent increasing numbers of notifications have raised several methodologic issues, which are examined in terms of: (1) the content of notification, (2) the process of notification, and (3) the evaluation of the impact and effectiveness of notification. Too often in the discussions concerning notification, attention is paid to the content but the process and evaluation are rarely considered. The potential impact and effectiveness of notification have been raised as reasons for or against notification, but rarely has there been a concerted effort to evaluate a notification in this regard. This workshop was designed to address all these issues. The ultimate goal is to improve communications for workers.

Key words: risk communication, worker notification, occupational risks, ethics, epidemiology

INTRODUCTION

Despite substantial literature on risk communication in the general population [Slovic, 1986; Fischoff, 1987; Covello et al., 1989; NRC, 1989; Baker, 1990] and on the communication of specific risks to workers [Samuels, 1979; Tepper, 1980; Coon and Polakoff, 1982; Schulte and Ringen, 1984; Needleman, 1990; Beauchamp et al., 1991], issues of methodology and evaluation are still pressing questions. Although there is consensus on the importance of risk communication in fulfilling citizens' right to know about risks and providing them opportunities to take action, how to do it properly is the subject of extensive discussion. Hence, the development, performance, effectiveness, and impact of risk communications are the topics of this workshop. We draw from a wide range of risk communication experiences but try to focus on the occupational case.

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It is useful to distinguish risk communication from hazard communication or health education. "Risk communication" is the directed transmission of information concerning the probability that an adverse event will occur [NRC, 1989; Baker, 1990]. In occupational environments, this is the probability that a worker will develop a given disease or experience an injury. "Hazard communication" is the dissemination of information that a chemical substance, physical or biological agent, or physical conditions can lead to disease if there is exposure [Baker, 1990]. "Health education" is the generalized dissemination of information on health and disease. It may be targeted to specific groups [Hanlon, 1974]. To some extent, risk communication to workers may involve hazard communication and health education. In general, at this workshop, the primary focus is on transmission of risk messages to specific workers. These messages indicate that they are part of a group at increased risk of disease. The history of risk communication by researchers in the National Institute for Occupational Safety and Health (NIOSH) has recently been characterized by the phrase "worker notification" [Baker et al., 1989]. This is the effort to inform workers who were subjects of epidemiologic studies of the overall results of those studies. Workers similarly exposed as those actually in a study also may be targets of these risk communications. Until the late 1980s, epidemiologists in general did not notify individual subjects of the results of epidemiologic studies. In NIOSH, routine dissemination by informing the companies and unions of results, publication in the scientific literature and in NIOSH documents, such as "Alerts," was considered sufficient. Prompted by congressional hearings in 1977 (Senate Committee on Human Resources, Subcommittee on Labor), NIOSH addressed the issue of whether and how to individually notify subjects of the results of completed epidemiologic studies [Schulte and Ringen, 1984; Bayer, 1987; Baker et al., 1989; Schulte, 1991].

In the ensuing years, NIOSH has established a practice of notifying subjects of epidemiological studies [Millar, 1988; Millar, 1989]. Today, companies and unions, and, in a few cases, academics and clinicians, are similarly notifying study subjects [CMA, 1991; Lerman et al., 1991; Lash et al., 1993; Sandman, 1991]. The question we all face, and the focus of this workshop, is how to conduct these types of notifications. The increasing number of individual notification efforts has raised a range of methodologic issues. These stem from the fact that, as with most epidemiologic data, the "risks" to be communicated are the risks to the group, yet the notification is to the individual, who generally wants individual risk information. The methodologic issues can be examined in three topic areas: (1) the content of notification, (2) the process of notification, and (3) the evaluation of the notification.

CONTENT

How can complex information be presented in a way that informs but does not alarm the recipient? What is the most appropriate way to present information so that recipients are motivated to take action but are still able to place their risks in perspective? For every notification letter that we have developed, there is always someone after reviewing it who wants to change the language. We have had many hours of negotiations with companies and unions and institutional review boards over the language of notification materials. Concerns have been expressed about the tone of a letter, the perspective on the risk, the best way to express uncertainty, the position of the "good" and "bad" news in the letter, the length of the letter, the subsets of

workers to receive the letters, the use of different letters for different exposure groups, and the signatories. In general, most letters for individual notifications go through a minimum of a dozen drafts. Our practice has been to keep the notification letters short and attach fact sheets with additional information on the study, steps to protect one's health, and information for the worker's personal physician. Is the use of supplemental fact sheets beneficial? Will such a mass of material be overwhelming to the workers? What reading level should be utilized? Are graphs helpful? Should a study with multiple plants have notification results in a plant-specific format in addition to overall study results? A key content area involves recommendations to those notified regarding steps they can take to protect their health or mitigate the risks. The recommendations can include: (1) reducing exposures, (2) providing information to their physician that can be considered with the other risk factors that the physician addresses (such as, obesity, smoking, alcohol consumption), (3) reducing exposure to additive or synergistic risks such as smoking, (4) obtaining medical screening, and (5) recognizing early symptoms and seeking timely treatment. Unfortunately, for some occupational diseases such as cancer, which has been the subject of many NIOSH epidemiologic studies, screening for asymptomatic workers has not been recognized as effective in reducing mortality. This is partly because the proper studies to ascertain the impact of screening on mortality generally have not been conducted and, in part, because current screening modalities do not detect cases early enough and therefore are not that efficient in leading to reduced mortality. Still, the concern by people notified is whether their health has been impaired. Unions, companies, and public health authorities are pressured or feel responsible to do something to show concern. Offering screening is often a surrogate for concern. How should the limitations of screening be discussed in notification materials? What other expressions of concern might be more appropriate?

A message about recommendations such as for screening or counseling is incomplete without discussion of how those services will be funded. Screening or counseling after notification is often not covered by personal health insurance and definitely not covered by workers' compensation for asymptomatic workers. How should questions of funding be addressed?

Other controversial issues that might be discussed in notification letters involve workers' compensation and legal rights of workers. For example, there is a question of whether there should be mention in notification messages that a notification could trigger worker compensation statutes of limitations. This has been a concern in the State of California, which has included language in its notifications on compensation information and advice to see a lawyer (Glenn Shor, personal communication). Should there be any mention in notification letters or materials of the legal rights of those notified?

PROCESS

Perhaps even more important than the content of notification is the process of communication to individuals. This includes the whole process of the development of materials, the choices of communication channels, the implementation of the notification, the provision of medical, social, psychological, financial, and legal support, and the involvement of the recipients of risk communications. The most important step in the process is involving those to be directly notified or affected. This involve-

ment reflects a shift in emphasis on risk communication during the last decade. The shift involves issues of trying to communicate technologically complex information to an audience that could not, or would not, grasp it to a new phase that puts emphasis on the process of risk communication [Leiss, 1989]. Of importance in the process is consideration of the perception of risk as well as the technical nature of the risk. Thus, the recipient of risk information is now recognized as having something of value to contribute to the process of achieving a social consensus on the management of risks [Slovic et al., 1980; Leiss, 1989].

The practice used by NIOSH researchers has been to develop notifications in concert with companies and unions. This has yielded a range of efforts and results, from prompt and effective communication, to long delays. In most cases, it has minimized apparent untoward effects in the short term. The most common channel of notification used by NIOSH researchers has been the use of written materials (letters and fact sheets). There has been less attention to the use of mass print and electronics media, newsletters, and meetings as channels for communications. We have long recognized that notification should not be just the sending of a message, but rather a process that deals with ameliorating the impact on those notified. What are effective ways of doing this? What roles should the different parties, such as employers and employee union local health officials, play? The establishment and maintenance of exposure registries and screening and monitoring programs may be the direct or indirect results of notification efforts [Schulte and Kaye, 1988; Marsh et al., 1991]. There is a need to assure that these activities are warranted and based on a firm scientific footing.

EVALUATION

There have been few formal evaluations of individual worker notification projects. Two aspects of a notification program can be evaluated: that relating to the effectiveness of the notification program in communicating its message, and that relating to its impact on the recipients and other stake holders. Those developing the notification materials are usually more concerned with the effectiveness of the notification (i.e., whether the message is reaching its intended audience with appropriate information for addressing the risk in question). Other societal groups, such as the companies and unions involved, are also particularly concerned with its impact. The evaluation of a notification should include both its effectiveness and its impact.

To evaluate the effectiveness of a notification, the objectives in conducting the notification should be defined prior to performing the notification. Those developing notification materials, especially those in public health roles, usually cite the objectives as fulfilling a subject's right to know, reducing risky exposures and behaviors, and encouraging appropriate and timely medical attention, be it medical screening, management, or treatment. While representing relevant positive objectives, these can fall short of addressing other consequences of risk messages. Are there other objectives in conducting notifications?

Although notifications have rarely been evaluated, they are often criticized for their presumed impact. Some of these potential impacts would be classified by everyone as adverse effects. Others would be classified as positive or negative effects depending on one's point of view.

For instance, negative psychological effects are often cited as reasons not to

conduct a notification. For example, in a recent evaluation by companies and unions of a notification for PCB-exposed workers of a fourfold excess of melanoma, a company expert claimed that a notification of this type constitutes a "once-in-a-lifetime" intense stressor for a majority of the recipients [Wood, 1990]. It was claimed that the PCB notification would result in three of the 3,189 individuals notified committing suicide. In another notification, there was concern that the notification would affect a person's credit rating, insurability, or employability [Schulte et al., 1985]. How can notifications be evaluated to assess whether these adverse effects occur and with what frequency? Companies have often been concerned that notifications could lead to extensive litigation. This has never been documented or studied systematically. In the Augusta notification [Schulte et al., 1985a], 169 workers filed ~ $300 million in litigation, but eventually settled for less than $1 million. This may be a worst case situation since this notification involved a group exposed to a chemical identified 20 years earlier as a potent bladder carcinogen. A fourfold excess risk of bladder cancer was found in the cohort, whose members had never been informed of its carcinogenicity [Schulte et al., 1985b]. In another joint industry-labor notification conducted for flint glass workers exposed to asbestos in Port Allegany, Pennsylvania, no litigation has been reported [Schulte and Ringen 1984].

Another area of concern is the impact a notification can have on the medical system. What pressure is put on a physician who receives a "Dear Doctor" letter that says the patient is part of a high risk group? Will the physician feel compelled to perform additional, inappropriate diagnostic tests on the subject? Who pays for this?

NOTIFICATION EFFORTS CONDUCTED BY NIOSH RESEARCHERS

NIOSH researchers have begun to address aspects of each of these topics (content, process, evaluation). For instance, we developed a General Notification Implementation Plan that describes the whole process of notification. Our guiding principle for notification is "tell them what we know." In actuality, this is not easy to do without controversy. For example, what we "know" from a study may be different from what a local union member "knows" from the shop floor, or what the management "knows" from its vantage point. "What we know" also depends on how broadly or narrowly we interpret relative risks, biological plausibility, or consistency of the findings. Through an iterative process, the views of labor, management, and NIOSH researchers are usually brought in line, and a mutually acceptable strategy is developed. In this process, language and recommendations for protecting health are modified. In order to assess whether workers can interpret notification materials, it is essential that they participate in the review process. When the actual workers are not available, surrogate groups have served in that role.

Regarding the process of notification, NIOSH researchers also have studied the role of exposure registries and screening programs. In the Drake [Marsh et al., 1991] and Augusta [Schulte et al., 1985] cohorts, these were examined and procedures and recommendations offered. Within that framework, notification or registry materials were reviewed by both companies and unions and by the NIOSH Human Subjects Review Board (HSRB). The HSRB reviews the content and form of each NIOSH notification prior to its issuance.

In terms of the evaluation of notifications, the approach we have used involves the use of a toll-free telephone number to allow for immediate questions and feedback

from those notified. In a recently mailed notification of 1,663 workers at risk of bladder cancer from o-toluidine, 40 calls were received. These primarily were requests for general information or for information on screening.

For a more systematic review of notification, we have awarded a contract recently to academic researchers to assess the long-term effects of the first notification in Augusta, Georgia, in 1981, as well as to develop and test an instrument that can be used in the future to assess the impact and effectiveness of selected recent notifications.

NIOSH staff have consulted with states, companies, trade associations, unions, academicians, and other government agencies about issues surrounding notification. Our experience, and the experiences of those with whom we have worked or discussed the matter, indicate that effective risk communication requires attention to the content, process, and outcome of notifications. We look to this workshop to provide some guidance in this area. It is out of this history, and these efforts, that the need for the workshop was perceived.

Despite this attention, there may be problems of risk communication for which very little can be done. These include problems: (1) pertaining to the reality of the message (i.e., no matter how you say it, a person may still be at risk, (2) resulting from the fact that risk messages necessarily compress technical information, which can lead to misunderstanding, confusion, and distrust, and (3) deriving from institutional or political systems [National Research Council, 1989].

This should not be taken to mean that risk communications cannot be improved or be effective. There is no single way of making risk communication easy [NRC, 1989]. However, attention to issues of content, process, and evaluation and the related issues discussed at this workshop should go a long way in improving risk communications to workers (and everyone else). That is our challenge.

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